Response to Revised Completeness Questions
HOSPICE SERVICES, BALTIMORE CITY
February 24, 2017

SUBMITTED BY:

CARROLL HOSPICE
292 Stoner Avenue, Westminster, MD 21157

TABLE OF CONTENTS

PART III

EXHIBITS

EXHIBIT 15 – VOLUNTEERS (QUESTION 6)

- BECOMING A VOLUNTEER BROCHURE
- DOULA VOLUNTEER PROGRAM TRAINING PACKET
- DIRECT CARE VOLUNTEER TRAINING MANUAL

EXHIBIT 16 – CAREGIVERS (QUESTION 7)

- PATIENT ORIENTATION FOR HOME HOSPICE
- WHEN THE TIME COMES BOOKLET
- WHAT TO EXPECT AT THE END OF LIFE RACK CARD
- FALLS PREVENTION BROCHURE
- SPIRITUAL CARE BROCHURE

EXHIBIT 17 – CAREGIVERS (QUESTION 7)

- WHEN YOU ARE GREIVING BROCHURE
- BEREAVEMENT SUPPORT SERVICES RACK CARD
- BEREAVEMENT SUPPORT SERVICES BROCHURE

EXHIBIT 18 - INFORMATION FOR PROVIDERS & THE GENERAL PUBLIC (QUESTION 9)

- CARROLL HOSPICE: A SPECIAL KIND OF CARING, GENERAL BROCHURE
- CARROLL HOSPICE INFORMATION AND STATS SHEET
- RIGHT CARE AT THE RIGHT TIME POWER POINT PRESENTATION
- CAMP TR, RETREAT FOR CHILDREN, RACK CARD
- VISIT CARROLL HOSPICE ONLINE RACK CARD

EXHIBIT 19 – QUALITY (QUESTION 13)

- QAPI CHARACTERISTICS CHART
- CARROLL HOSPICE QUALITY IMPROVEMENT AND PATIENT SAFETY PLAN

EXHIBIT 20 – NEED (QUESTION 15D)

- MAP: LIFEBRIDGE HEALTH SERVICE AREA ZIP CODE DEFINITION

CARROLL HOSPICE

February 24, 2017
Response to Revised Completeness Questions
Dated 2/3/17

E-mail and USPS Mail

William D. Chan, Health Policy Analyst
Maryland Healthcare Commission

**Re: CON Application to Establish General Hospice in Baltimore City
Carroll Hospice – D.N. 16-23-2388**

Dear Mr. Chan:

Below are Carroll Hospice's response to completeness questions pertaining to our Certificate of Need ("CON") application to establish a general hospice in Baltimore City, Maryland.

PART 1 – PROJECT IDENTIFICATION AND GENERAL INFORMATION

1. Will there be a local office located in Baltimore City, and if so, please provide the address?

   Applicant Response: Yes. While the actual office location has not been determined yet, we anticipate that this office will be located on the campus of Sinai Hospital, which is in Baltimore City.

2. Please provide more details on the type of education that Carroll Hospice, working with LifeBridge Health, will provide to build broader acceptance of hospice care with the African American and Orthodox Jewish communities. How will Carroll Hospice address such issues as community culture, acceptance of hospice services, cultural mistrust and religious tradition by the African American and the Orthodox Jewish communities?

   Applicant Response: Carroll Hospice's plan for education and outreach in Baltimore City and across our service area is multi-faceted and will include:

   a. Robust end of life care education and training for providers across disciplines and across care settings. Plans are already in place for Carroll Hospice to serve as a clinical site for the Sinai Hospital residency training program.

b. Community education on hospice care, caregiving, grief and loss using multiple diverse strategies: health fairs, senior center presentations, printed materials and newsletters, website modules, and social media.

c. Educational offerings provided to discharge planners, case managers and post-acute care coordinators in healthcare institutions to promote timely access to care.

d. Carroll will draw on the religious leaders/community members who helped develop the inpatient hospice unit at Sinai to assist them in being responsive to the Orthodox community's needs and to also help design home hospice services to be presented and delivered most responsively

e. Carroll will draw on chaplaincy services at Sinai Hospital to help speak with patients

f. Carroll will actively involve the religious leadership of the Interfaith Health Network that serves Baltimore communities in determining the best locations/best times for education/outreach programs

g. Carroll will involve the Interfaith Health Network in extending their activities to recruit community members/volunteers to support home hospice patients and their families

h. Creation of a spiritual care advisory board to guide the work of the hospice in promoting access and overcoming barriers to hospice care prominent in the African American and Jewish communities.

i. Developing a consistent message for the business community to position hospice as an option to support their employees as caregivers

j. In conjunction with other services in Baltimore City, broaden the number of support groups offered by Carroll Hospice to provide, at a minimum, two additional offerings: (1) Support for those who have experienced a loss related to substance abuse and (2) Mending Hearts – a program to support those who have experienced the loss of a child.

k. Collaborating with nursing facilities to provide education designed specifically for staff, residents, and family councils of nursing homes and assisted living communities.

l. In alignment with complimentary services in Baltimore City broaden, at minimum the offering of 2 key Carroll Hospice support groups; Support for those who have experienced a loss related to substance abuse and Mending Hearts – a program to support those who have experienced the loss of a child.

m. Collaborating with nursing facilities to provide education for key providers, staff, residents and family councils on hospice care specific to nursing homes and assisted living communities.

PART III – CONSISTENCY WITH GENERAL REVIEW CRITERIA AT COMAR 10.24. 01.08G(3)

Minimum Services

3. Please indicate whether Carroll Hospice will directly employ skilled nursing care, medical social services, and counseling services.

   Applicant Response: Carroll Hospice will directly employ skilled nursing, medical social services and counseling services consistent with Medicare Hospice Conditions of participation.

4. For physician services and medical direction, the applicant states, "as the volumes build, medical oversight will be expanded proportionally." Please clarify whether additional physician services will be provided through direct employment or contractual arrangements.

   Applicant Response: Carroll Hospice has traditionally contracted with physicians for this position. We expect the same will be true for any expansion of those responsibilities for Baltimore City.

5. Please indicate whether Carroll Hospice will provide each of the following services through direct employment or via contractual arrangements:

   - hospice aide
   - homemaker services
   - spiritual services
   - on-call nursing response
   - personal care
   - bereavement services

   Applicant Response: Carroll Hospice will directly employ providers for spiritual services, on-call nursing response services, hospice aid services, homemaker services and bereavement services but may also need to contract for hospice aid positions at times of high census, which also provide homemaker and personal care services.

Volunteers

6. Please provide details as to the type of training that Carroll Hospice will provide to volunteers.

Applicant Response: Every volunteer for Carroll Hospice is required to attend a six-week, 21-hour training program. Each volunteer is provided a comprehensive manual as part of that training for future reference. A copy of this manual is attached as **Exhibit 15** along with Carroll Hospice's Volunteer brochure and the Doula Volunteer Training packet.

Caregivers

7. Please discuss whether Carroll Hospice will provide, in a patient's residence, appropriate instruction to, and support for, persons who are primary caretakers for a hospice patient.

Applicant Response: Caring for a hospice patient in his or her home allows those patients to receive the care they need in a familiar setting. Carroll Hospice offers home hospice care 24 hours a day, seven days a week.

While their loved one is enrolled in Carroll Hospice, the hospice staff provides support for family members with day-to-day caregiving responsibilities including:

- Training for the caregiver(s) to help them understand(s) the patient's individualized plan of care;
- Pain and symptom management;
- Personal care for the patient;
- What to expect during the dying process;
- When to call for help, and
- Resources available through Carroll Hospice.

Carroll Hospice staff reviews information with the caregiver(s) but also provides written material for their reference. See **Exhibit 16** for copies of written materials. If an immediate need arises, an on-call nurse will address the concern or make a home visit.

When appropriate, Carroll Hospice also will actively involve the religious leadership of the Interfaith Health Network that serves Baltimore communities to help support home hospice patients and their families.

For patients in our current service area, through our inpatient and partner facilities, we offer respite care—a short break from the responsibilities of caregiving. We plan to offer respite options to our Baltimore City families through existing inpatient facilities close to the patient's home.

Applicant Response: Carroll Hospice also provides bereavement support for at least 13 months following the death of a patient. Written material as well as individual and group counseling for adults and children are available along with a resource-filled bereavement center. See **Exhibit 17** for copies of this written material.

Impact

8. Please provide more specific information to support your statement that "Carroll Hospice will invest heavily in patient education and activity with the Faith Health Network across Baltimore City." What strategies and tactics will be employed?

Applicant Response: Carroll Hospice will work closely with faith community leaders and the Interfaith Network to identify specific needs in their congregations, educate volunteers on end of life care options and identify champions within those communities. By doing so, Carroll Hospice expects to develop an advocacy network of respected, trusted voices to assist community members in accessing quality, end of life care tailored to an individual's unique needs and preferences.

Carroll Hospice also will work closely with the staff and volunteers at Sinai and Northwest hospitals to design education programs that engage potential volunteers.

Information to Providers and the General Public

9. Please provide the links to your website, or submit copies of brochures, written materials, or presentations that provide general information on the current hospice program serving Baltimore, Carroll, and Frederick Counties.

Applicant Response:

Carroll Hospice's Web site address is **CarrollHospice.org**

We have attached an informational presentation and various promotional brochures we use for promoting services to the community, our patients and families including (See **Exhibit 18**):

- Overview Brochure for Carroll Hospice "A Special Kind of Caring"
- Info and Stat Sheet w/ General information about Carroll Hospice
- The Right Care at the Right Time – Power Point Presentation

Charity Care and Sliding Fee Scale

10. Please provide Carroll Hospice's Time Payment Plans for low-income patients who do not qualify for full charity care.

Applicant Response: Patients who do not qualify for Charity Care or other non-hospital based assistance are offered a payment plan. Payment amounts and term vary, are flexible and determined by the amount owed and the patient's ability to pay. It is important to note, that although there is a process for patients who do not qualify for Charity Care, no patient requiring hospice care is ever denied access to hospice care based on his or her ability to pay.

As outlined in Exhibit 2 of our original application, Carroll Hospital and Carroll Hospice's Financial Assistance policy clearly states that patients who request financial assistance will be qualified based on the Eligibility Criteria listed in the policy, including Medical Financial Hardship and Presumptive Financial Assistance Eligibility, which takes into account certain criteria not covered in the general Eligibility Criteria including:

- Medical debt incurred by the family over a 12-month period
- Participation in WIC Programs
- Eligible for and receiving Food Stamps
- Eligible for and participating in Subsidized School Lunch Programs
- Eligible for and participating in Affordable or Subsidized Housing Programs

Carroll Hospice will work with patients who still do not qualify for Financial Assistance based on the above criteria on an individual basis, ensuring there is no delay in providing care.

11. To demonstrate Carroll's commitment to providing charity care services, please disclose Carroll Hospice's level of charity care for the last 5 years?

Applicant Response: Carroll Hospice has provided $55,000 in charity care services over the last 5 years (Fiscal Years 2012 – 2016). In addition to charity care services, Carroll Hospice assists uninsured Hospice clients obtain Medicaid coverage when appropriate. Over this same time period, Carroll Hospice has obtained Medicaid coverage for 73% of the uninsured clients that have been referred for Hospice (38 clients).

12. Does Carroll Hospice currently have a specific plan in place that will help to achieve the level of charity care to which it is committed, and if so, please provide details.

Applicant Response: Carroll Hospice plans to utilize the same method of qualifying patients for and providing Charity Care as it does currently. Every patient referred to Carroll Hospice will be admitted to our service following the same processes, which includes determining eligibility for Financial Assistance.

Quality

13. Please document that Carroll's QAPI is consistent with the requirements of COMAR 10.07.21.09 by responding to the attached table to document how the applicant's QAPI plan meets each of the QAPI elements measured by OHCQ.

Applicant Response: –See **Exhibit 19**.

Linkages with Other Service Providers

14. Please identify which home health agencies, assisted living providers, Adult Evaluation and Review Services (AERS), Senior Information and Assistance Programs, adult day care program(s), local Department of Social Services, and home-delivered-meal programs in Baltimore City that the applicant has contacted regarding the proposed hospice program.

Applicant Response: To date, Carroll Hospice's contact with the above referenced providers has been minimal and limited to those affiliated with the LifeBridge Health System. As indicated in our original application, Carroll Hospice intends to reach out to organizations outside of its own system after it is awarded a CON. As soon as licensure has been awarded, Carroll Hospice plans to utilize its strong network of providers, services and programs throughout Baltimore City to reach out to key agencies and organizations.

Need

15. Please respond to the following:

a. Regarding the table on p. 28, please clarify the years reported and the sources for the data on this table. The table's title states that the data is for the years 2012 thru 2014, but the table reports data for 2013 thru 2015. In addition, there is some confusion as to source, since hospice use rates are indicated for the year 2012, but no source cited for 2013 in the table.

Applicant Response:

The data on page 28 represents 2013-2015 data, as the column headings had indicated. The title for this Table has been edited to indicate that the data below reflects the 2013-2015 time period.

The data sources include the following:

(1) Number of hospice deaths by County, 2013-2015: MHCC Long Term Care Survey

(2) Hospice use rates by County, 2013: "County Use Rates for Hospice Care," MHCC http://mhcc.maryland.gov/mhcc/pages/hcfs/hcfs_hospice/documents/chcf_hospice_heo_Use_Rate_Trend_2007_2013.pdf

(3) Hospice use rates by County, 2014: Based on State of Maryland Vital Statistics, Deaths Age 35+ years, by County

(4) Hospice use rates by County, 2015; based on NHPCO Edge, LLC, Hospice Market Share and Service in Maryland, 2015; A state-wide Report by Jurisdiction

County Use Rates for Hospice Care, 2013 – 2015

County	Measure	2013	2014	2015
Allegany	# Hospice Deaths	163	195	174
	Hospice Use Rate	0.18	0.22	0.19
Anne Arundel	# Hospice Deaths	1,996	1,926	1,707
	Hospice Use Rate	0.51	0.49	0.42
Baltimore City	# Hospice Deaths	1,848	1,434	1,433
	Hospice Use Rate	0.31	0.25	0.22
Baltimore County	# Hospice Deaths	4,024	4,321	4,554
	Hospice Use Rate	0.54	0.56	0.56
Calvert	# Hospice Deaths	226	223	254
	Hospice Use Rate	0.37	0.37	0.39
Caroline	# Hospice Deaths	66	89	92
	Hospice Use Rate	0.22	0.27	0.30
Carroll	# Hospice Deaths	753	730	802
	Hospice Use Rate	0.52	0.50	0.53
Cecil	# Hospice Deaths	395	379	367
	Hospice Use Rate	0.46	0.46	0.39
Charles	# Hospice Deaths	287	265	268
	Hospice Use Rate	0.33	0.29	0.27
Dorchester	# Hospice Deaths	77	75	82
	Hospice Use Rate	0.22	0.20	0.21
Frederick	# Hospice Deaths	738	735	886
	Hospice Use Rate	0.47	0.46	0.51
Garrett	# Hospice Deaths	75	63	73
	Hospice Use Rate	0.25	0.23	0.22
Harford	# Hospice Deaths	850	966	991
	Hospice Use Rate	0.47	0.51	0.48
Howard	# Hospice Deaths	730	766	789
	Hospice Use Rate	0.49	0.49	0.48
Kent	# Hospice Deaths	81	111	65
	Hospice Use Rate	0.34	0.46	0.41
Montgomery	# Hospice Deaths	2613	2601	2,836
	Hospice Use Rate	0.47	0.47	0.47
Pr George's	# Hospice Deaths	1288	1430	1,400
	Hospice Use Rate	0.26	0.28	0.24
Queen Anne's	# Hospice Deaths	151	200	173
	Hospice Use Rate	0.40	0.49	0.35
Somerset	# Hospice Deaths	81	66	88
	Hospice Use Rate	0.32	0.25	0.36
St. Mary's	# Hospice Deaths	310	338	316
	Hospice Use Rate	0.41	0.47	0.40
Talbot	# Hospice Deaths	195	167	82
	Hospice Use Rate	0.46	0.37	0.23
Washington	# Hospice Deaths	725	817	800
	Hospice Use Rate	0.48	0.57	0.53
Wicomico	# Hospice Deaths	403	422	412
	Hospice Use Rate	0.45	0.46	0.46
Worcester	# Hospice Deaths	246	235	296
	Hospice Use Rate	0.42	0.40	0.46
Total, State of MD	# Hospice Deaths	18,321	18,554	18,940
	Hospice Use Rate	0.42	0.43	0.40

b. Regarding the table on p. 29, provide a clear narrative on how the data for 20 14-2015 shows underutilization of hospice services by the African American population since there is no correlation with hospice utilization overall in Baltimore City.

Applicant Response: The original table on page 29 presents the following comparison of figures, by County:

- The percentage of total hospice deaths represented by African Americans
- The percentage of total adult deaths represented by African Americans

The data from page 29 is reproduced in the table on the following page, with the columns re-ordered (using the very same data) to present this point more clearly. The data shows the following for Baltimore City:

- While African Americans represented 68% of *total* Baltimore City adult deaths (2014), African Americans represented only 55-57% of Baltimore City *hospice* deaths (2014-2015). The differential suggests that African Americans are "underrepresented," i.e. are not utilizing hospice care to the level that population figures, by themselves, would project. Baltimore City and Dorchester County are the only two counties where the discrepancy is greater than 10 percentage points.

Note: For CY2014, data for both the number of adult deaths and the number of hospice deaths were available for comparison. In CY2015, data to document hospice data was available, but data on the total number of hospice deaths was not available. However, the CY2015 hospice data was included here to highlight that hospice volume for African Americans did not increase in CY2015, but in fact declined.

Hospice Deaths: African Americans, as Percentage of Population, Age 35+
2014-2015

	African Americans % of Hospice Deaths		African Americans % of Deaths in Population age 35+	
County	2014 % Hospice Deaths	2015 % Hospice Deaths	2014 % of Population Deaths	2015 % of Population Deaths
Baltimore City	57%	55%	68%	N/A
Prince George's	60%	60%	67%	N/A
Charles	28%	26%	32%	N/A
Somerset	26%	14%	25%	N/A
Dorchester	14%	21%	25%	N/A
Wicomico	14%	15%	20%	N/A
Howard	12%	16%	20%	N/A
Baltimore	22%	22%	17%	N/A
Kent	12%	9%	17%	N/A
Montgomery	14%	13%	16%	N/A
St. Mary's	13%	14%	15%	N/A
Calvert	11%	10%	14%	N/A
Worcester	11%	11%	14%	N/A
Talbot	7%	6%	13%	N/A
Anne Arundel	15%	15%	13%	N/A
Queen Anne's	7%	8%	12%	N/A
Caroline	6%	13%	12%	N/A
Harford	7%	7%	8%	N/A
Frederick	5%	5%	7%	N/A
Cecil	5%	5%	5%	N/A
Washington	3%	3%	4%	N/A
Carroll	3%	2%	2%	N/A
Allegany	3%	0%	1%	N/A
Garrett	0%	1%	0%	N/A
Total, State of MD	**21%**	**21%**	**27%**	

Sources:

(1) Deaths, by Race and by Age Cohort: Maryland Administration of Vital Statistics

(2) Hospice deaths: MHCC Hospice Survey

c. Regarding p. 30, identify which hospice providers, long-term care professionals, physicians, and case managers were included in discussions, and how the applicant collected this information regarding cultural and religious traditions that discourage hospice utilization. Does the applicant have evidence to support the statements regarding "mistrust of hospice referrals, community culture, and possibly weaker home supports," or are these issues anecdotal or conjecture.

Applicant Response: The basis for these statements were based on evidence provided by the following:

(1) Discussions with health care professionals/social services professionals in Maryland whose assessments were remarkably consistent
(2) Report issued by the MHCC that explicitly cited cultural and religious factors as barriers to hospice utilization
(3) Reports/presentations posted on the MHCC website and understood to be recognized by the MHCC as expert analyses and /or evidence-based practice

1. ***Discussions conducted with health care providers/social services professionals*** - In the course of our assessment, discussions were conducted with clinicians and social services providers who care for patients in the ambulatory, inpatient, home care and long-term care settings. Discussions were held with providers of acute care, palliative care, home care, hospice care, social work and discharge planning services. This group included professionals working in the LifeBridge network and professionals working outside of the LifeBridge network. Discussions were conducted individually with the following providers[1]:

LifeBridge Health-affiliated

- Cancer Institute at Sinai Hospital, Physician Director
- Cancer Institute at Sinai Hospital, Hematology, Physician
- Inpatient Palliative Care, Sinai Hospital, Program Director
- Inpatient Palliative Care, Sinai Hospital, Program Coordinator and Social Work services
- Social Work, Sinai Hospital, Director
- Carroll Hospice, Executive Director (prior experience: 22 years at Gilchrist Hospice)
- Levindale Hebrew Geriatric Center and Hospital, Chief Operating Officer
- Post-Acute Physician Partners (PAPP), Physician
- Post-Acute Physician Partners (PAPP), Executive Director

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[1] Note: Interviews were also conducted with a Baltimore City home care provider and with 2 major payers; however, the focus of these discussions was not on barriers to hospice utilization

Professionals at local Baltimore City hospitals

- Bon Secours Hospital, Director of Outcomes Management, Social Work and Case Management
- St. Agnes Hospital, Director of Social Work

When asked about the significant opportunities to improve end-of-life care, these professionals consistently responded with statements about the huge opportunity to increase utilization of hospice services. When asked about current barriers, professionals consistently cited the need for more physician education, and virtually all interviewees referred to one or more of the following factors as a major barrier in the Baltimore City community: Community culture, religious traditions, mistrust of hospice referrals, and/or misperceptions of hospice care that have functioned to discourage hospice utilization.

These statements reflect years of experience working in the Baltimore community and, for several professionals, their assessment reflects a comparison base of hospice service delivery in other regions of Maryland. These professionals are not ones who work in isolation, simply compiling and comparing utilization statistics; these are physicians, social workers, and discharge planners who interact with patients, who listen to patients, who work to understand and support patient/family decision-making. Their observations and their assessments are based upon and represent direct evidence of the factors affecting decision-making by patients and families.

2. ***MHCC report, June 2014***– Carroll Hospice has also based its statements on evidence provided directly by the MHCC that explicitly cites cultural barriers, religious principles, mistrust of health care providers, and myths (i.e. misperceptions) as factors tied to underutilization of hospice services by the African American community. Excerpts, that serve as evidence, are cited below:

- Presentation material by Linda Cole, Chief of Long Term Care Policy and Planning, MHCC, to the Hospice Education and Outreach Work Group: "Review of Preliminary Baltimore City Hospice Meeting" (October 28, 2014)[2]
    - "There are substantive religious, cultural and ethnic barriers to use of hospice"
    - "There are myths to overcome"
    - "Need to work with faith-based community"
    - "Presence of minority staff can improve trust building"
    - "Themes from Literature" that are consistent with these themes in Baltimore City

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[2] http://mhcc.maryland.gov/mhcc/pages/hcfs/hcfs_hospice/documents/chcf_hospice_mhcc_presentation_baltcity_20141028.pdf

- "Barriers to hospice use:
    - Conflicting values with hospice philosophy
    - Lack of information on hospice
    - Concerns about burdening the family
    - Mistrust of the healthcare system
    - Expectation that hospice employees would not be minority
    - Hospice means 'giving up' "

3. ***Reports by national experts posted on the MHCC website*** - Numerous presentations are posted on the MHCC website and therefore recognized to be reports by those with expertise in the field. These reports provide evidence to support factors such as religious tradition, community culture and mistrust of health care referrals discourage hospice use among minority communities. Selected statements from these reports are excerpted below:

- NHPCO presentation: "Inclusion and Access: NHPCO's Diversity Initiative" (June 9, 2015)[3]
    - Discussion of "Cultural Differences Matter"
        - Acceptance levels of hospice care are affected by "accepted religious and spiritual beliefs, practices and rituals"

- National Hospice and Palliative Care Organization, Caring Connections. "African American Outreach Guide" (2008)[4]
    - "Generally, there is a conflict between wanting to be informed medically, but being culturally bound to privacy and wanting to turn to and rely on faith first and foremost..........There was significant distrust that even if preferences are specified in writing, that the medical professional in charge would not honor them."

- Baltimore Sun article and Washington Post article posted on the MHCC website citing studies from across the country that identify cultural beliefs and religious principles as key factors affecting hospice use. One illustration:

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[3] http://mhcc.maryland.gov/mhcc/pages/hcfs/hcfs_hospice/documents/chcf_hospice_heo_NHPCO_prst.pdf

[4] http://www.caringinfo.org/files/public/outreach/African_American)Outreach)Guide.pdf

- "Studies suggest that one barrier to broader hospice use among African Americans is a set of broad cultural beliefs that touch on religion and attitudes toward the health care system."[5]

d. Please provide a map that shows the zip codes in Baltimore City that are listed in Exhibit 10.

Applicant Response: See **Exhibit 20**.

e. Regarding the referral channels mentioned on pp. 35 through 39, please quantify the number of projected cases that the listed LifeBridge Health programs, various hospitals and facilities may refer to Carroll Hospice for end-of-life care.

Applicant Response:

Referral channels: The LifeBridge delivery system
The strength of the LifeBridge Health System to the proposed hospice program is the Health System's many points of contact where patients may be introduced to hospice care, plan for hospice and/or from where they may be transferred directly to hospice. The list of referral channels presented on pages 35-39 reflects this point: This list presents (a) community-based points of contact where patients, friends, family, religious leaders, and community leaders may learn more about hospice, and become potential referral channels for patients (b) service settings where providers and patients prepare advance plans for hospice, and (c) points in the continuum from where patients are transferred directly to hospice.

LifeBridge patients with chronic conditions and end-stage disease are likely to transition across program components; therefore, it is difficult to tie hospice referrals to any single referral source. However, in response to the question above, each of these referral channels is defined more specifically below accompanied by a high level estimate of referral volume on the summary table following. This summary table limits volume projections to Baltimore City patients, only, and discounts total volume potential to acknowledge that Carroll Hospice will be one of several choices presented to patients.

- Disease management programs, senior care programs and LifeBridge physician practices
  - Current service sites now provide patient care and referral; emerging programs will provide an even greater focus on patient education, advance

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[5] http://mhcc.maryland.gov/mhcc/pages/hcfs/hcfs_hospice/documents/chcf_hospice_mhcc_presentation_baltcity_20141028.pdf

care planning and family supports. These programs/provider practices will be a broad-based, high volume, and steady source of referrals to home care, palliative care, long-term care and hospice services. Hospice volume is projected through the categories below.

- Palliative Care program, Sinai Hospital
  - The inpatient consultation service currently provides more than 100 inpatient consultations per month and, consistent with industry trends, is expected to grow. Hospice volume is projected based on the assumption that 30% of patients served will transition to hospice.
- Lapidus Cancer Institute, Sinai Hospital
  - The total number of unduplicated Baltimore City patients with a cancer diagnosis served at LifeBridge is documented to be 745 patients (Year). Hospice volume is projected based on the assumption that 30% of patients are provided palliative care and 30% of these patients transition to hospice care.[6]
- HomeCare of Maryland
  - Hospice volume is projected based on the assumption that 2-3% of Baltimore City home care patients will transition to hospice.
- Post-Acute Physician Partners
  - PAPP physicians currently work at four nursing homes located in Baltimore City where hospice utilization is tracked. The opportunity to improve quality of care by increasing hospice use rates was estimated using a 10% target use rate for hospice care in nursing homes. Hospice volume is projected based on the *incremental volume* associated with increasing hospice volume from current levels to the 10% level.
- Nursing Home Collaborative and PAPP expansion
  - LifeBridge has championed a nursing home collaborative of 30 nursing homes in Maryland to monitor quality indicators and improve quality of care for nursing home patients. A core initiative is to bring organized and structured hospice programs to as many nursing homes as possible. Two of these nursing homes are located in Baltimore City, where PAPP physicians and Carroll Hospice expect to work.

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[6] Projected volume from the Cancer Institute is then discounted to avoid double counting of cases from the Palliative Care and Cancer Institute referral channels.

Referral channels: Other hospitals/other community providers in Baltimore City

As noted throughout the application, Carroll Hospice intends to conduct provider training and community outreach programs across Baltimore City; these activities are expected to produce an increase in the overall number of hospice referrals from hospitals and provider groups across Baltimore City. Carroll Hospice will serve a significant portion of this new program volume as a function of provider-to-provider relationships, high quality program reputation, timely responsiveness to referral requests, and contract relationships with Medicare Advantage plans and ACOs. High-level estimates are presented to reflect the balance of Carroll Hospice's projected program volume expected to be drawn from hospitals serving Baltimore City patients.

Hospice volume from area hospitals were projected based on the current number of deaths in the hospital of adult patients with a cancer diagnosis and of Medicare patients with any one of the following chronic disease diagnoses: Heart failure, ischemic heart disease, COPD, chronic kidney failure, Alzheimer's disease and related disorders. The assumption was made that 25-30% of these deaths - - representing the highest volume diagnostic groups within hospice settings- - might be candidates for hospice. Hospice referrals from those hospitals with hospice program affiliations (i.e. Mercy, GBMC, and Hopkins hospitals) were excluded on the premise that Carroll Hospice would draw only a negligible percentage of referrals from these hospitals.

A summary of high-level estimates for hospice referrals to Carroll Hospice, by referral channel, is presented on the page following. Overall program volume was projected based on the MHCC's volume projection for Baltimore City, and Carroll's projection for market share. The volume projections presented below, by referral channel, demonstrate the robust referral sources for Carroll Hospice; the specific volume represent a "reasonableness check" to support that the overall volume projection is achievable.

HOSPICE REFERRAL VOLUME

Source	Assumptions / Estimates	Range	Midpoint Estimate
LIFEBRIDGE HEALTH AFFILIATED SOURCES			
Disease management & senior care programs; LifeBridge physicians	Programs and service sites will serve a high volume patient base of Medicare and chronic disease patients. Programs will provide patient care, education, advance care planning, and referral; programs will integrate with Carroll Hospice, functioning to increase hospice use rates.	0	0
Palliative Care program, Sinai Hospital	Current: 1,200 inpatient consults/year Projected: 1,300-1,400 inpatient consults/year, 1.2 Consults/patient • 50% = Baltimore City patients • 30% transition to hospice, 80% select Carroll	130-140	135
Lapidus Cancer Institute, Sinai Hospital	Unduplicated adult patients, Baltimore City residents, with cancer diagnosis = 745 •30% provided palliative care and 30% then transition to hospice; 80% patients select Carroll = 54 •20-30% already accounted for above in Palliative Care Incremental = 38-43	38-43	40
HomeCare Maryland	Current: 1,100 Baltimore City patients/year • 2-3% transition to hospice; assume 80% select Carroll	18-26	22
Post-Acute Physician Partners (PAPP)	Physician services at: Levindale, FutureCare Lochearn, ManorCare Roland Park •Total Admissions 750-800 •Incremental growth of hospice utilization to 10% of total admissions	75-80	77
Nursing home collaborative and PAPP program expansion	Collaborative includes additional Baltimore City nursing homes with opportunity for structured, organized hospice program •Total admissions @ 2 nursing homes = 1,328 •10% hospice utilization x 80% served by Carroll	106	106
	TOTAL LIFEBRIDGE HEALTH AFFILIATED		**380**
NON-LIFEBRIDGE HEALTH AFFILIATED SOURCES			
Projected shift of hospital deaths to hospice setting	Baltimore City adult residents now dying in hospitals: Adults with cancer + Medicare patients with 1 of 4 high volume chronic care diagnoses represented in hospice. Total 1,087 patients Hospitals/Systems with hospice affiliation: Mercy, GBMC, JHH, JHBMC = 253 deaths Sinai & Northwest Hospitals = 183 deaths (Accounted for above) All other hospitals = 651 deaths •30-40% may be candidates for hospice •30% choose Carroll	0 - 58-78	0 - 68
Dual Eligibles	In Baltimore City = 29,000 •30% enrollment and 0.5-1.0% hospice use is incremental, 20% choose Carroll	9-17	13
	TOTAL NON-LIFEBRIDGE HEALTH AFFILIATED		**81**
	Estimated 2016 volume		461
	All Other/Population Growth		21
	APPROXIMATE 2020 TARGET		**482**

f. Regarding the projected utilization for Carroll Hospice's integrated program reported in Table 13 on p. 47, please provide a breakdown of the projected utilization by jurisdiction (i.e., Baltimore, Carroll, and Frederick Counties and Baltimore City).

Applicant Response: The Table below provides a breakdown of projected unduplicated admissions by jurisdiction.

Unpuplicated Admissions
Projection Period

Jurisdiction	**FY 2018**	**FY 2019**	**FY 2020**
Carroll County	809	837	863
Frederick County	120	125	131
Balt. County	48	50	52
Balt. City	123	290	482
All Other	11	11	12
Total	**1,111**	**1,313**	**1,540**

Availability of More Cost Effective Alternatives

16. Please discuss why Carroll Hospice is a more cost effective alternative than either Stella Maris, Gilchrist Center Baltimore Joseph Richey House, Seasons Hospice, Heartland Hospice, PHR of Baltimore Hospice, Amedisys Hospice of Greater Chesapeake, or either Carroll Hospice or Bayada Hospice to meet the projected future need for hospice services in Baltimore City.

Applicant Response:

A. Reducing the total costs of care - Hospice care provided by Carroll Hospice will serve as a more cost effective alternative to current models of service delivery by minimizing the number of end-of-life hospitalizations and reducing the total costs of care. Savings will be achieved by:

- Increasing *the number* of Baltimore City patients utilizing hospice, thereby reducing hospital spending for end-of-life hospitalizations
- Introducing hospice care earlier in the plan of care to *extend the enrollment period* in hospice, increase patient satisfaction, and further minimize hospital utilization (i.e. maximizing the value of hospice care)

- Providing palliative care, wrap-around services and supports at home and in the nursing home setting so that caregivers *do not feel pressured to admit patients* to the hospital

The opportunity potential to reduce the costs of care is very significant. A high-level analysis was prepared to assess the magnitude of hospital spending that may be avoided through hospice care. The analysis examined Medicare deaths of patients who were coded with chronic disease diagnoses in order to document the hospital utilization for these patients and the potentially avoidable utilization/hospital spending as hospice utilization increases. The analysis adopted CMS-defined chronic conditions, but this comprehensive list was narrowed considerably to a more limited number of diagnostic groupings and age bands to represent a more realistic candidate pool for hospice care. The analysis then examined:

- Hospital charges for the final hospitalization (i.e. discharge ending in death in the hospital)
- Hospital charges in the 1 month period prior to death
- Hospital charges in the 6 month period prior to death

Detailed findings are presented in the table below. Summary findings highlight the significant opportunity potential for reducing hospital spending through hospice care:

- Hospital spending for the final hospitalization – Assuming that 20-30% of patients in these defined groups are served by hospice, and that the average spending for the final hospitalization is avoided, this would produce approximately $ 8-13 million of avoided hospital spending for Baltimore City patients.

- Hospital spending for the one month prior to death – Assuming that 20-30% of these hospital costs were avoided for this patient population with chronic diseases (patients who now die in the hospital) through election of hospice; this would amount to a $10-15 million reduction in hospital spending during the 1 month period prior to death.

Deaths in Maryland Hospitals
Baltimore City Adult Residents
Selected Diagnostic Groupings

Hospital charges associated with Medicare deaths, selected diagnoses
Adults, only

	Number of cases	Total charges, final hospitalization	Average charge	@ 20% hospice users	Potentially avoidable final hospitalization	@ 30% hospice users	Potentially avoidable final hospitalization
Deaths with cancer diagnoses, age 20+ years	290	$ 11,668,309	$40,236	58	$ 2,333,662	87	$ 3,500,493
Deaths with selected chronic conditions, age 65+ y	801	$ 30,716,268	$38,347	160	$ 6,143,254	240	$ 9,214,880
TOTAL	**1,091**	**$ 42,384,577**	**$38,849**	**218**	**$ 8,476,916**	**327**	**$ 12,715,373**

Hospital charges 1 month prior to death
Adults, only

	Number of cases	Total charges, 1 month prior	Average charge	@ 20% hospice users	Potentially avoidable 1 month hospital charges	@ 30% hospice users	Potentially avoidable 1 month hospital charges
Deaths with cancer diagnoses, age 20+ years	290	$ 14,042,327	$48,422	58	$ 2,808,465	87	$ 4,212,698
Deaths with selected chronic conditions, age 65+ y	801	$ 37,713,706	$47,083	160	$ 7,542,741	240	$ 11,314,112
TOTAL	**1,091**	**$ 51,756,033**	**$47,439**	**218**	**$ 10,351,207**	**327**	**$ 15,526,810**

Source: HSCRC Abstract Dataset

Notes:
(1) Definitions for chronic conditions based on diagnostic groupings defined by CMS in "Chronic Conditions Warehouse."
(2) Selected diagnostic groups used for this analysis: Heart failure, ischemic heart disease, chronic obstructive pulmonary disease, chronic kidney disease, Alzheimer's disease and related disorders
(3) Patients of all adult ages with cancer diagnoses assumed to be likely candidates for hospice; patients with other chronic conditions who are candidates for hospice limited to population age 65+ years old

B. Ability to initiate hospice earlier on to maximize value – Relative to other applicants, Carroll Hospice is better-positioned to engage, build trust, and introduce hospice care earlier in the end-of-life care model. As a member institution of LifeBridge Health, Carroll Hospice will be able to (a) introduce its programs through ongoing community-based programs and interfaith community activities, (b) integrate its program with disease management programs/protocols, home care services and oncology services at LifeBridge, (c) integrate its program with palliative care and advance care planning at

LifeBridge hospitals, and (d) work closely with the PAPP program as PAPP expands its activity across post-acute facilities in Baltimore City. Carroll's position within a larger health system is a distinct advantage for program success.

C. Evidence of minimizing readmissions - Carroll Hospice has the record of accomplishment to demonstrate it knows how to minimize hospital admissions once a patient has elected hospice and can provide the more cost effective alternative: Carroll Hospice reports a markedly low readmission rate for its hospice patients while maintaining high patient satisfaction.

D. Cost efficient program operations - Carroll Hospice is strongly positioned to operate a cost-efficient program for Baltimore City by leveraging its existing infrastructure, extending many of its existing resources, and drawing on LifeBridge resources for community services, advance care planning, spiritual care, interfaith community programs, and provider education.

E. Costs to payers - From the payer perspective, Carroll Hospice will operate comparably to existing hospice providers in Baltimore City. This is based on the fact that the large majority of hospice patients are Medicare patients, and Medicare payments are fairly consistent across hospice providers in the City. For non-Medicare patients, and Medicare pays a per diem rate based on the level of hospice care (four levels: routine home care, continuous home care, inpatient respite care, and general inpatient care) adjusted for specific locality. Therefore, payment rates for hospice providers in Baltimore City would be consistent. From the patient perspective (i.e. nom-Medicare patients), the similar premise will operate; non-Medicare patients would have similar rates regardless of hospice provider in Baltimore City.

F. Incentives to promote cost effective care – Under the Maryland Demonstration Model, LifeBridge Health will be moving toward accountability for the total costs of care in its service area. In this context, hospice level of care will be an extremely valuable component in the continuum of care and will be promoted as integral component to cost effective care management.

As a part owner of a Medicare Advantage product (through Priority Partners), LifeBridge providers will be further incentivized to integrate hospice into the continuum of care:

- LifeBridge providers will be strongly encouraged to manage the costs of care under Medicare Advantage; hospice will function as a powerful component to cost effective service delivery.

- Medicare Advantage plans are accompanied by publicly reported quality and performance ratings (i.e. akin to Hospital Compare), and Priority Partners will need to demonstrate high patient satisfaction and cost effective performance. Hospice care will empower patients, provide enrollees with an additional option for care while maintaining continuity of care, improve the quality of care, and support high ratings from families/patients enrolled.

Therefore, even as all hospice programs are comparably reimbursed, Carroll Hospice presents distinct advantages to *promote* cost effective service delivery in Baltimore City. Stated simply, Carroll Hospice is better positioned relative to other hospice applicants to be *utilized* cost effectively. LifeBridge will effectively integrate hospice providers and electronic health records for seamless transitions, and Carroll Hospice will help patients/families to experience care transitions more seamlessly and less painfully inasmuch as end-of-life care is sorrowful. LifeBridge providers will utilize Carroll Hospice effectively as they operate under increasingly "accountable" payment models and consumer-oriented models, and Carroll Hospice will work as partners with hospital-based and community-based providers - - with aligned incentives - - sharing in the results of the health system's overall performance.

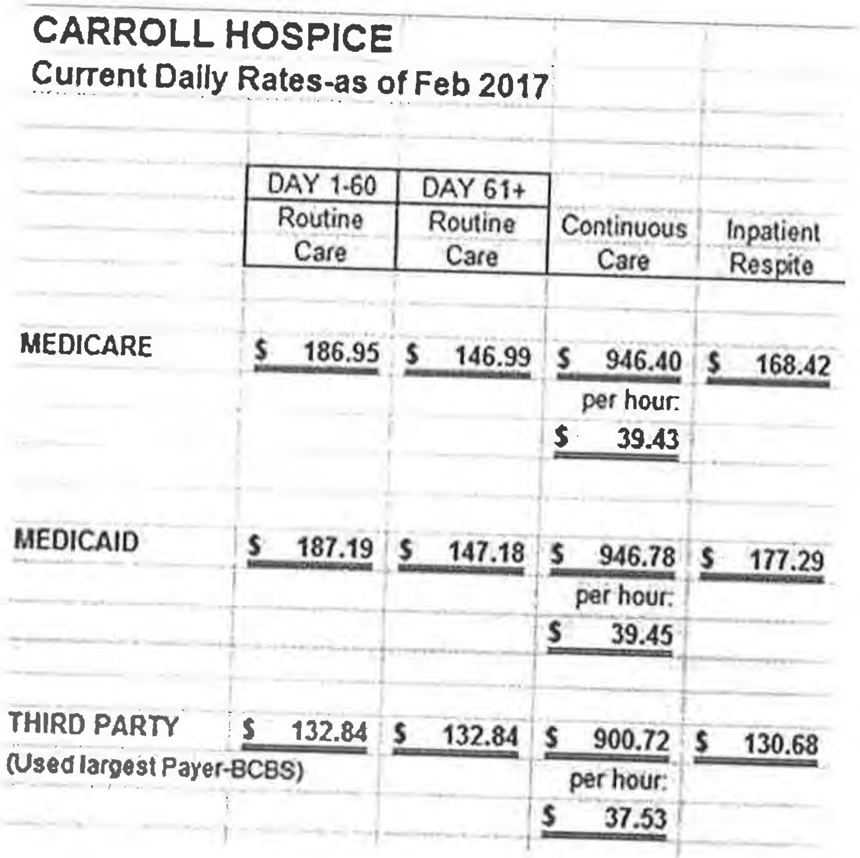
Viability of the Proposal

17. Please cite the source for the funds that will finance the cost of establishing Carroll Hospice in Baltimore City.

Applicant Response: Carroll Hospice is a wholly owned subsidiary of Carroll Hospital (a member of LifeBridge Health). The cost of establishing Carroll Hospice in Baltimore City will be funded through existing operating cash reserve funds of Carroll Hospice and Carroll Hospital.

18. Please provide Carroll Hospices' proposed daily rate for routine home care, continuous home care, and inpatient respite care for Medicare, Medicaid, and third party payers.

Applicant Response:



CARROLL HOSPICE
Current Daily Rates-as of Feb 2017

	DAY 1-60 Routine Care	DAY 61+ Routine Care	Continuous Care	Inpatient Respite
MEDICARE	$ 186.95	$ 146.99	$ 946.40 per hour: $ 39.43	$ 168.42
MEDICAID	$ 187.19	$ 147.18	$ 946.78 per hour: $ 39.45	$ 177.29
THIRD PARTY (Used largest Payer-BCBS)	$ 132.84	$ 132.84	$ 900.72 per hour: $ 37.53	$ 130.68

Impact on Existing Providers

19. Provide evidence that supports your position that the establishment of Carroll Hospice in Baltimore City will improve performance on quality indicators for Maryland hospitals, nursing homes, ACOs, and physicians.

Applicant Response: The increase in overall hospice utilization rates will be accompanied by increased quality scores across the continuum of providers as a function of the following:

(A) Improvements tied to hospice program initiatives, Citywide –Carroll Hospice will dedicate resources to provider training and community education programs across the City. This will function to increase overall hospice utilization rates, improve quality of care and patient satisfaction, and lead to improved performance on quality indicators across facilities/providers:

- Increased hospice utilization will be tied to broader-based provider training programs across Baltimore City, and will lead physicians to engage in meaningful, supportive discussion time with patients

- Increased hospice utilization will be accompanied by a reduction in hospital admissions and increased use of palliative care. The reduction in hardships to patients, the reduction in hospital-acquired infections, and the reduction in costs to patients will result in improved quality of life and higher patient satisfaction scores (as measured across the continuum). The increased use of palliative care should also translate into improved quality scores, as numerous studies have shown that use of palliative care results in higher patient satisfaction.

- Increased hospice utilization will be accompanied by declines in hospital mortality rates.

- Increased hospice utilization will be accompanied by greater supports provided to families, including families of nursing home patients. Quality indicators for nursing homes should improve, as family members are often the individuals completing quality/satisfaction reports for patients in the long-term care setting.

- Increased hospice utilization is integrally tied to patient empowerment. This factor, along with increased use of palliative care and home-based care, is understood to contribute to higher patient satisfaction. Evidence to support this includes a recent study by researchers at Harvard Medical School who evaluated nearly 2,000 cancer patients - - half of whom received hospice care and half of whom did not - - and showed hospice patients to report higher patient satisfaction levels and to be more likely to report that their end-of-life wishes were fulfilled.[7]

(B) Improvements tied to Carroll Hospice program, specifically - As a high performing provider with stellar patient satisfaction scores, Carroll Hospice is particularly well positioned to improve patient satisfaction and improve performance on quality indicators across the continuum.

- Carroll Hospice will be closely integrated with the Palliative Care Program at Sinai Hospital and the advance care planning functions for inpatients. This will contribute to patient empowerment and higher patient satisfaction of hospital patients.

---

[7] "Research Shows Higher Patient Satisfaction from Hospice Care," Journal of Clinical Oncology (January 2016?) http://ascopubs.org/doi/full/10.1200/JCO.2016.68.9257

- Carroll Hospice is committed to encouraging/training providers to introduce the hospice option earlier in end of life care. In fact, this may be a critical factor in improving patient and family satisfaction. The very same study of cancer patients cited above indicates that patients receiving hospice care for a longer period of time are more likely to have end-of-life patient satisfaction. According to researchers, patient satisfaction is dependent upon the duration of the service. Higher patient satisfaction levels correlated with longer lengths of stay in hospice, most notably when patients entered hospice care 30 or more days prior to death. Researchers emphasized the value of enrolling patients in hospice care earlier in end-of-life care. [8] Carroll Hospice, working together with the larger LifeBridge Health delivery system, is particularly well positioned to deliver this value to patients, which will translate into improved quality indicators.

- Carroll Hospice will be integrated with ambulatory, acute care, post-acute and home care programs across LifeBridge facilities to support smooth transitions across levels of care. The transition to hospice will not be experienced as a sudden and displacing event. This is expected to result in higher patient satisfaction scores across hospitals.

- Carroll Hospice will provide culturally competent provider teams, which will result in higher patient satisfaction with providers.

- Carroll Hospice provides family support services as well as bereavement services. This will serve to improve satisfaction scores, particularly in the long-term care setting, where families may complete surveys in place of patients.

Table 3

20. Please explain the dramatic loss of income from operation for FY 2016 and the subsequent turnaround in FY 2017.

Applicant Response: During FY 2017, Carroll Hospice net patient services revenues are projected to increase 25% - or $1.5 million. This revenue growth is attributable to a 27% increase in client volume levels (projected daily census (ADC) of 115 during FY 2017 compared to an ADC of 91 during FY 2016). Growth in ADC is a function of an estimated 5% growth in unduplicated admissions and longer lengths of stay (44 days currently vs 36 days in prior year). As Carroll Hospice has been able to successfully attract additional clients (and to provide end of life services earlier), Carroll Hospice has also been able to successfully accommodate this growing patient base in a cost-effective manner. Over this same time period, Carroll Hospice has been able to limit expense growth to 11% compared to FY 2016 (or $775k) – as fixed costs are spread over a larger client base.

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[8] ibid

Table 5

21. What position(s) are included as "Other Support" at a total cost of $194,582?

Applicant Response: The positions identified as "Other Support" at a total cost of $194,582 on Table 5 of the application include a provision for an Office Manager (1) and Intake Coordinators (2).

We are submitting our responses in both Word and PDF format, to Ruby Potter (ruby.potter@maryland.gov). We also have provided affirmation forms for the following individuals responsible for submitting these responses:

Regina Bodnar
Cris Coleman
Teresa Fletcher
Miriam Suldan

Should you have any questions regarding these responses, please contact me at (410) 871-7650.

Sincerely,

Regina S. Bodnar

Regina S. Bodnar,
Executive Director
Carroll Hospice

AFFIRMATION

I hereby declare and affirm under the penalties of perjury that the facts stated in the foregoing responses to February 3, 2017 Completeness Questions of Carroll Hospice are true and correct to the best of my knowledge, information and belief.

Regina M. Bodnar

Name: Regina M. Bodnar

AFFIRMATION

I hereby declare and affirm under the penalties of perjury that the facts stated in the foregoing responses to February 3, 2017 Completeness Questions of Carroll Hospice are true and correct to the best of my knowledge, information and belief.

Name: Cris Coleman

AFFIRMATION

I hereby declare and affirm under the penalties of perjury that the facts stated in the foregoing responses to February 3, 2017 Completeness Questions of Carroll Hospice are true and correct to the best of my knowledge, information and belief.

Name: Teresa A. Fletcher

AFFIRMATION

I hereby declare and affirm under the penalties of perjury that the facts stated in the foregoing responses to February 3, 2017 Completeness Questions of Carroll Hospice are true.and correct to the best of my knowledge, information and belief.

Miriam Suldan

Name: Miriam Suldan

Exhibit 15

Volunteers

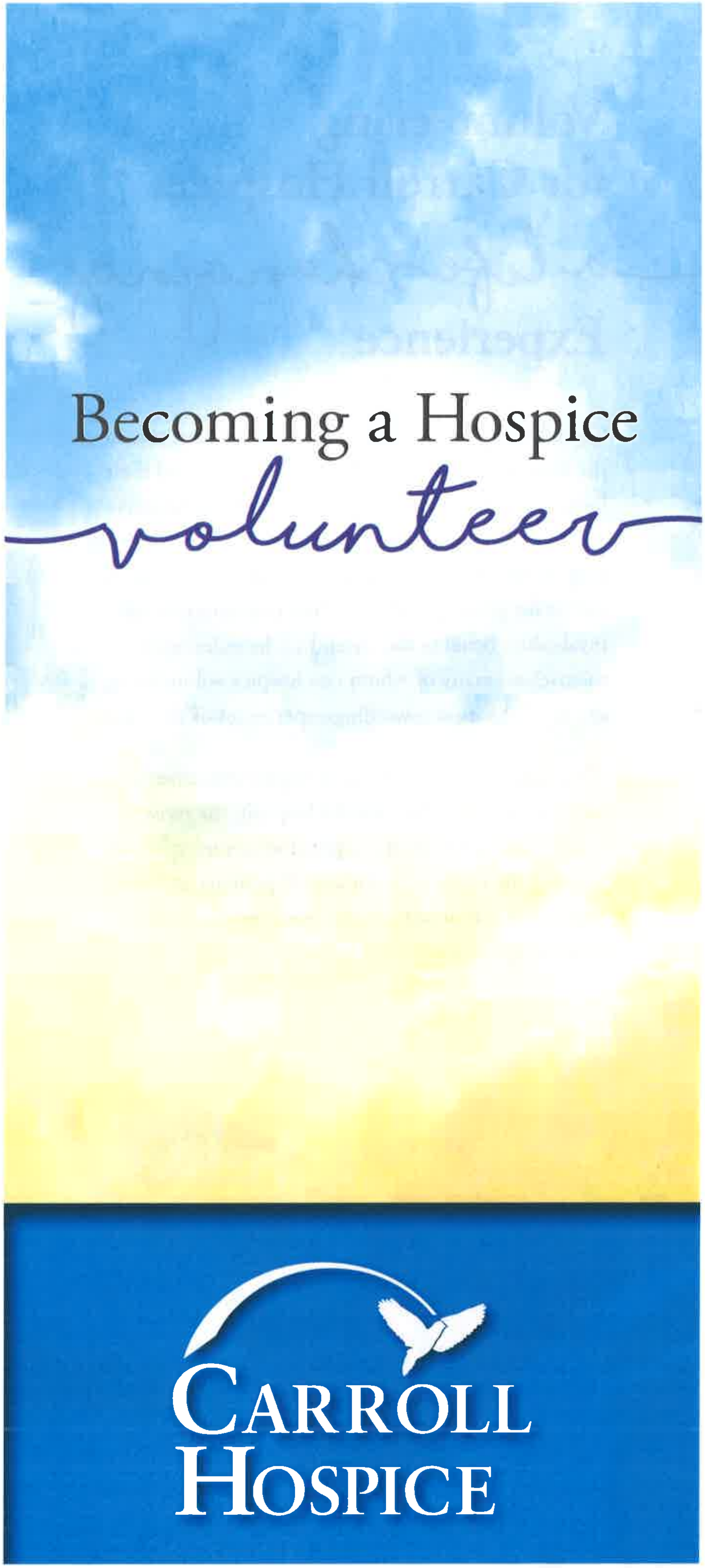
(Question 6)

Becoming a Volunteer Brochure

Doula Volunteer Program Training Packet

Direct Care Volunteer Training Manual

Becoming a Volunteer Brochure



Becoming a Hospice volunteer

CARROLL HOSPICE

Volunteering for Carroll Hospice: a life-changing Experience

Carroll Hospice volunteers play an important role in the lives of those with life-limiting illnesses and their loved ones. Whether working directly with patients and families, providing administrative and fundraising support or serving as a camper "buddy" at our annual retreat for grieving children, their contributions are invaluable. Benefits also extend to the volunteers themselves, many of whom cite hospice volunteering as one of the most rewarding experiences of their lives.

While some volunteer positions require extensive training (provided by Carroll Hospice), the most important qualification is a genuine commitment to meeting the needs of terminally ill patients and their loved ones. Volunteers do not need any previous hospice experience.

What opportunities are available?

Our volunteers serve Carroll Hospice in many capacities depending on their talents, interests and availability. Here are some of the ways they make a difference:

- **Patient care** – These volunteers serve as companions and helpers for patients and their families, either in private residences, Carroll Hospice's inpatient facility (Dove House) or health care settings such as nursing homes and assisted living communities. Specific duties may include providing respite care to family members, running errands or simply spending time reading, talking and listening to patients. Patient care volunteers must be 18 years of age or older.
- **Doula** – Our inpatient facility welcomes the use of doula volunteers to sit with patients in their final moments of life. Our specially trained volunteers offer comfort and a supportive presence at that time.
- **Veterans** – A participant in the We Honor Veterans program, Carroll Hospice has implemented a variety of programs to educate staff and the community about the needs of veterans and to recognize their contributions. Military veterans are needed to visit with and honor veteran patients for their dedicated military service to our country.
- **Fundraising and special events** – Carroll Hospice relies on volunteers to help organize and support key fundraising and outreach events that help us fulfill our pledge to care for all patients, regardless of their ability to pay.
- **Administrative** – Office volunteers assist with a variety of tasks that help Carroll Hospice function smoothly, including filing, letter and electronic correspondence, fielding phone calls or serving as a greeter or receptionist at our inpatient facility and other clerical duties.

- **Professional** – Carroll Hospice is grateful for the many professionals who donate their time and services for the betterment of our patients. Professional volunteers include, but are not limited to, massage therapists, hair stylists, Reiki practitioners and music therapists. These volunteers must have a current license or certification in their area of expertise.
- **Pet therapy** – The unconditional love and attention from a pet help bring smiles and comfort to our patients. Those who have trained, or would like to train, their pet by a pet therapy organization may volunteer to visit patients in their homes, assisted living facilities or our inpatient facility. The volunteer coordinator can help facilitate choosing a training program if needed.
- **Camp T.R.** – A weekend retreat for children grieving the loss of a loved one, Camp T.R. combines recreational activities, such as art, swimming and music, with grief education and support. Volunteers are needed to serve as camper "buddies" and assist with logistics and planning. A one-day training session is required.
- **Groups and donations** – We offer a variety of customized volunteer opportunities for service and church groups.

What about training and support?

Patient care volunteers and those working in our inpatient facility are required to take a six-week training course (21 hours total). This course may be required or recommended for those volunteering in other capacities as well. The training helps participants better understand a patient's needs and prepares them for the issues they may encounter while serving as a Carroll Hospice volunteer.

Interested in volunteering?

To learn more about volunteering or to arrange an interview, please call our volunteer coordinator at 410-871-7228.

About Carroll Hospice

Serving patients in Carroll, Frederick and Baltimore Counties.

An affiliate of Carroll Hospital, Carroll Hospice has been providing high-quality, patient-centered care to terminally ill individuals and their loved ones for more than 30 years. Through specialized nursing services, along with spiritual and emotional support, Carroll Hospice helps patients live out the remainder of their days in dignity, in the warmth and familiarity of their own home, a health care setting or our beautiful inpatient facility. For grieving family members, Carroll Hospice offers a host of resources, including bereavement counselors, a comprehensive bereavement center with a resource library and support groups for all ages. Carroll Hospice is accredited by the Community Health Accreditation Program (CHAP).

It is encouraged that surviving family members wait a minimum of one year following the loss of a loved one before volunteering.

CARROLL HOSPICE

Home hospice | Inpatient hospice | Bereavement support
Serving Carroll, Baltimore & Frederick counties

A non-profit affiliate of Carroll Hospital, a LifeBridge Health center

292 Stoner Avenue
Westminster, Maryland 21157
410-871-8000 | 888-224-2580
410-876-8044 from Baltimore
410-871-7186 TTY | 410-871-7242 Fax
CarrollHospice.org

We Honor Veterans

HOSPICE
HONORS

CHAP

Doula Volunteer Program Training Packet

CARROLL
HOSPICE

Doula Volunteer
Program

Doula Volunteer Program Development

1. Program Description/Summary

The Doula Volunteer Program will provide a compassionate presence while a patient is actively dying. The volunteer will support patients/caregivers both spiritually and emotionally, and offer guidance and comfort during this transition. This program will aid to fulfil the philosophy that no one should die alone.

This program will provide spiritual support and maintain the patient's comfort and dignity during their final hours. If family is present, this program will offer emotional support and guidance. Should family need to leave the patient's bedside, this volunteer will remain sitting vigil. This volunteer could simply accompany family members if they are not comfortable being with the patient at the time of death.

These volunteers may be a presence in silent reflection, play soft music, provide gentle touch, or offer prayer, in addition to being an advocate for the patient and determine any needs.

2. Needs Assessment

- Support from IPU staff and other team members?
- Aid in training?
- Concerns?
- Suggestions?

3. Policies & Procedures

- Criteria for Volunteers
    - Complete Direct Care Training
    - Experienced with end of life (personal experience or through Hospice volunteering)
    - Undergo application process, and be approved by Volunteer Coordinator
    - Understand that they may be called at any time for an assignment
    - Complete additional ~~11th Hour~~ Doula Training
- How It Will Work – Logistics
        - Availability
        - Length of Visit
        - Safety
        - Communication with Dove House
        - Reporting
- Staff protocol
    - Notification of when a patient is transitioning
        - Patient's condition
        - Time to be covered – 3-4 hour blocks of time, overnight request
    - After hours contact information
    - Family requests
        - Family's status – are they coming, contact person, preferences
        - Patient preferences – scripture reading, music, lotion/scents

Carroll
Hospice

CARROLL HOSPICE PROGRAM

VOLUNTEER POSITION DESCRIPTION: Doula Volunteer

Reports to: Volunteer Coordinator

Classification: Category 2

Job Purpose: To provide support services to patients and families through support at the time a patient is actively dying.

Job Responsibilities:

- Provide support, comfort, and companionship to patients and caregivers through multiple techniques including active listening, prayer, hand holding (light massage).
- Demonstrate understanding of the dying process in order to facilitate the needs of the patients and families.
- Provide a comforting presence to patients at any time needed so that the patient is not alone.
- Advocate for the patients as needed.

Qualifications:

- Completion of Carroll Hospice Volunteer Training Program and be an active Direct Care Volunteer.
- Completion of Carroll Hospice Doula Volunteer Training Program
- Must be able to maintain appropriate personal and professional boundaries
- Must be at least 18 years of age

Expectations:

- Respect the beliefs and privacy of others.
- Understand that volunteer may be called at any time for an assignment
- Maintain open communication with other team members including other doula volunteers, In-patient staff, and volunteer coordinator.
- Adhere to all guidelines, policies and procedures.
- Complete proper documentation and annual compliance requirements.

At the time of death:

Holy God, We thank You for giving *[-----]* to us to know and to love on our earthly journey. Now we gently place ***"him / her"*** into Your loving arms. Accept ***"him / her"*** into Your heavenly kingdom to live forever in that place that You have prepared especially for ***"him / her"***. And be with *[------'s]* family in the days and weeks that lie ahead. Surround them with Your peace, Your strength, and Your love. Help them to know that You are always with them. All these things we pray in Your Holy Name.

Amen.

At the time of death:

Holy God, We thank You for giving *[-----]* to us to know and to love on our earthly journey. Now we gently place ***"him / her"*** into Your loving arms. Accept ***"him / her"*** into Your heavenly kingdom to live forever in that place that You have prepared especially for ***"him / her"***. And be with *[------'s]* family in the days and weeks that lie ahead. Surround them with Your peace, Your strength, and Your love. Help them to know that You are always with them. All these things we pray in Your Holy Name.

Amen.

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Amen.

At the time of death:

Holy God, We thank You for giving *[-----]* to us to know and to love on our earthly journey. Now we gently place ***"him / her"*** into Your loving arms. Accept ***"him / her"*** into Your heavenly kingdom to live forever in that place that You have prepared especially for ***"him / her"***. And be with *[------'s]* family in the days and weeks that lie ahead. Surround them with Your peace, Your strength, and Your love. Help them to know that You are always with them. All these things we pray in Your Holy Name.

Amen.

Bible Verses About Death: 20 Comforting Scriptures Quotes

Posted By *Pamela Rose Williams* On June 14, 2011 @ 9:07 pm In Bible,Bible Verses,Quotes | 168 Comments

One of the most difficult things to deal with in life is the death of a loved one. Even for the Christian, death is a part of life. Unlike they that do not believe, the Christian has a blessed hope [1] – that is the return of the Savior Jesus to catch up His Church and bring them to eternal life with Him and God the Father in Heaven [2]. Here are some scripture quotes about death that I hope will comfort you .

As He Promised, He Will Do

John 14:1-4 *"Let not your hearts be troubled. Believe in God; believe also in me. In my Father's house are many rooms. If it were not so, would I have told you that I go to prepare a place for you? And if I go and prepare a place for you, I will come again and will take you to myself, that where I am you may be also. And you know the way to where I am going."*

Romans 8:16-17 *The Spirit himself bears witness with our spirit that we are children of God, and if children, then heirs—heirs of God and fellow heirs with Christ, provided we suffer with him in order that we may also be glorified with him.*

2 Corinthians 5:6-8 *So we are always of good courage. We know that while we are at home in the body we are away from the Lord, for we walk by faith, not by sight. Yes, we are of good courage, and we would rather be away from the body and at home with the Lord.*

1 Thessalonians 4:16-18 *For the Lord himself will descend from heaven with a cry of command, with the voice of an archangel, and with the sound of the trumpet of God. And the dead in Christ will rise first. Then we who are alive, who are left, will be caught up together with them in the clouds to meet the Lord in the air, and so we will always be with the Lord. Therefore encourage one another with these words.*

1 Thessalonians 5:9-11 *For God has not destined us for wrath, but to obtain salvation through our Lord Jesus Christ, who died for us so that whether we are awake or asleep we might live with him. Therefore encourage one another and build one another up, just as you are doing.*

2 Samuel 12:23 *But now he is dead. Why should I fast? Can I bring him back again? I shall go to him, but he will not return to me." (King David speaking of his infant son who died)*

John 11:23-26 *Jesus said to her, "Your brother will rise again." Martha said to him, "I know that he will rise again in the resurrection on the last day." Jesus said to her, "I am the resurrection and the life. Whoever believes in me, though he die, yet shall he live, and everyone who lives and believes in me shall never die. Do you believe this?"*

1 Corinthians 15:54-57 *When the perishable puts on the imperishable, and the mortal puts on immortality, then shall come to pass the saying that is written: "Death is swallowed up in victory." "O death, where is your victory? O death, where is your sting?" The sting of death is sin, and the power of sin is the law. But thanks be to God, who gives us the victory through our Lord Jesus Christ.*

Philippians 3:20-21 *But our citizenship is in heaven, and from it we await a Savior, the Lord Jesus Christ, who will transform our lowly body to be like his glorious body, by the power that enables him even to subject all things to himself.*

HAIL HOLY QUEEN
Hail, holy Queen, Mother of mercy, our life, our sweetness and our hope. To thee do we cry, poor banished children of Eve: to thee do we send up our sighs, mourning and weeping in this valley of tears. Turn then, most gracious Advocate, thine eyes of mercy toward us, and after this our exile, show unto us the blessed fruit of thy womb, Jesus. O clement, O loving, O sweet Virgin Mary!
Leader: Pray for us O Holy Mother of God,
All: That we may be worthy of the promises of Christ.
(Optional)
Leader: Let us pray.
All: O God whose only begotten Son by his life, death, and Resurrection has purchased for us the rewards of eternal life; grant we beseech thee, that meditating on these mysteries of the Most Holy Rosary of the Blessed Virgin Mary, we may imitate what they contain and obtain what they promise through the same Christ our Lord. Amen.

PRAYER FOR THE HOLY FATHER (FOR PRIVATE DEVOTION)
Leader: Upon this Rock He will build His Church...
All: ...and the jaws of death shall not prevail against her.

Leader: O Mother of the Redeemer...
All: ...Living Tabernacle of the Eucharist, and Luminous Rose of Heaven, with humble confidence we ask you to bestow upon the Holy Father all the graces and blessings reserved for him by the Holy Trinity from all eternity. Amen.

Leader: Help his friends...
All: ...convert his enemies.

Leader: Saint Joseph...
All: ...pray for us. Amen.

The Twenty Mysteries

Here is a brief listing and description of all twenty Mysteries.

THE JOYFUL MYSTERIES

- *The Annunciation:* The Archangel Gabriel "announces" to Mary that she shall conceive the Son of God.
- *The Visitation:* Mary visits her cousin Elizabeth, who is pregnant with John the Baptist.
- *The Nativity:* Jesus is born.
- *The Presentation:* Mary and Joseph "present" Jesus in the Temple where they meet Simeon.
- *The Finding in the Temple:* After losing Him, Mary and Joseph find young Jesus teaching the Rabbis in the Temple.

THE LUMINOUS MYSTERIES (THE MYSTERIES OF LIGHT)

- *The Baptism in the Jordan:* The voice of the Father declares Jesus the beloved Son.
- *The Wedding at Cana:* Christ changes water into wine, his first public miracle.
- *The Proclamation of the Kingdom:* Jesus calls to conversion (cf. Mk 1:15) and forgives the sins of

intention. Some people offer particular intentions before each decade. You can ask God to grant you a favor, heal a sick person, or convert a sinner. Some people offer the same intention every day--sometimes for years on end--especially when asking the Father for the conversion of a particular person. Intentions are as varied as the people who pray.

Ask for big and small gifts. Be bold! In this sense, the Rosary is an exchange of gifts between friends.

It is widely known that Our Lady answers seemingly impossible intentions to those who are first beginning to pray the Rosary. This is her way of drawing you closer to Her and to Jesus. If you are praying your first Rosary, or returning to the Rosary after years of not talking to Our Lady, ask for something big, spectacular, "impossible." She'll often surprise you.

Meriting a Plenary Indulgence

The Catholic Church, exercising its authority to "bind and loose on heaven and earth," and in perfect accord with God's Mercy, has set the following conditions for the granting of a plenary indulgence for those who pray the Rosary:

- Be in a state of grace--that is your soul is free from mortal sin.
- Be free from attachment to--that is, not in the habit of--venial sin.
- Go to confession several days before or after praying the Rosary.
- Receive Holy Communion on the day you pray the Rosary.
- Say a prayer for the Pope.

By fulfilling these simple (but often difficult) conditions, you merit the grace to release one soul from Purgatory. While we are free to ask God to apply this grace to a particular soul, God can do as he pleases, according to His Will and Mercy. You can also ask God to apply this special grace to your own soul. A plenary indulgence will relieve the temporal punishment due to sin (it will not absolve the sin or cause the sin to be forgiven).

The Full Rosary

A "full Rosary" consists of saying all twenty decades, that is, all four sets of five Mysteries. A "Rosary" consists of praying five decades of one set of Mysteries. Many people pray a full Rosary every day; either by praying four separate Rosaries in the morning, midday, afternoon, and evening; or all twenty Mysteries at one time (it is not necessary to repeat the preamble--the Apostles Creed, etc.--between the four sets of Mysteries if one is praying a full Rosary. Conclude with Hail Holy Queen after the last of the Glorious mysteries).

The Family Rosary

The Family Rosary is usually prayed out loud after dinner or before going to bed. Family members can take turns "leading" the decades with one person praying the beginning of the prayers, and all others praying the endings. Some families announce intentions before they begin the Rosary; others take turns announcing special intentions before they begin the Rosary; others take turns announcing special intentions before the beginning of each decade. Many families add favorite prayers at the end of the Rosary, or ask favorite saints and angels to pray for them.

The Art of Personal Presence

In a paper entitled "Some Reflections on Personal Presence" by Jack Marquis the author identifies some techniques to being present with another.

1. Being present to another is an extremely difficult task.
2. Learn to be with the person, rather than try to solve the problem.
3. Understanding others is enough. There is no need to solve problems. Understanding others is truly a standing under, and uplifting of the other.
4. Allow the other to have his pain. Learn to enter into it with the other rather than try to take it away.
5. Learn to hear not only the content of another's message, but also his feelings and emotions about the content.
6. Responding to the whole person means at the least responding to feelings and emotions as well as thoughts and ideas.
7. When you feel lost in an interaction, ask yourself: "What is this person trying to reveal to me about himself?" "What is the meaning or purpose of this person's communication to me?"
8. Respond to the other rather than react. Reacting means meeting the other's feelings with your feelings. Responding means meeting the other's feelings with understanding.
9. When we are aware of our own feelings we can respond to others rather than react to them.
10. Being aware of one's own feelings is not an end in itself, but a means to choosing a behavioral response that is appropriate to the present situation.
11. When we say to the other, "I understand" it is a clear sign that we don't.
12. Learn to hear the conflict within the other rather than become part of the conflict by taking sides.
13. The more strongly the other is asserting his point, the more certainly he is arguing with himself. To agree or disagree is not the issue, but to help the other become aware of his conflict within.
14. Learn to receive the other; to make room in oneself for the other's pain. This can only be done when we have first of all accepted our own pain.
15. When we feel revulsion or any other negative feelings toward another person it is most likely because their behavior threatens exposure of something within ourselves that we are unwilling to accept about ourselves.
16. As we grow in being able to make room for the other within ourselves, the other will grow.
17. To minimize another's feelings about his life is to discount the other.
18. Being present to another is not the same thing as being nice to the other. Being nice is often a form of discounting the other, of not taking seriously his irritating or demanding behaviors that mask his pain.
19. If we want to help others, we must accept our poverty; that we have nothing really saving to give but our presence.

Direct Care Volunteer Training Manual

CARROLL
HOSPICE

Direct Care Volunteer
Training Manual

Orientation

Our Mission

Carroll Hospice is a non-profit organization dedicated to improving the quality of life for patients needing end-of-life care, by allowing them to live as fully and comfortably as possible while providing quality palliative care, pain and symptom management and support for their families.

Our Philosophy

- Provide patients with palliative care and effective pain symptom management.
- Help patients experience peace, comfort and dignity during the end stage of life.
- Allow patients to make their own decisions regarding care and treatment.
- Promote a caring community sensitive to the needs of hospice patients and their families.
- Support family members and other caregivers in their efforts to care for their loved one.
- Coordinate community resources to ensure continuity of care.
- Offer bereavement support to families.

Our Spirit Values

Our actions and decisions are guided by these core values:

SERVICE	exceed customer expectations
PERFORMANCE	deliver efficient, high quality service and achieve excellence in all that we do
INNOVATION	take the initiative to make it better
RESPECT	honor the dignity and worth of all
INTEGRITY	uphold the highest standard of ethics and honesty
TEAMWORK	work together, win together

Modern Hospice Movement

1969 Dame Cicely Saunders founded St. Christopher's in suburban London. St. Christopher's would become the model for modern hospices.

Components of St. Christopher's Hospice

1. Weekly interdisciplinary team meetings to include physicians, nurses, psychiatrists, pharmacists, clergy, social workers, and volunteers.
2. Family oriented patient care.
3. Bereavement support with relatives after patient death.
4. Encouraged concept of death as normal, natural event in life.

1960's Dr. Elizabeth Kubler-Ross, a psychiatrist delineated five "stages of dying":

1. Denial
2. Anger
3. Bargaining
4. Depression
5. Acceptance

1963/1964 Dame Saunders came to the U.S.A. sharing her vision for care of terminally ill with Americans. Florence Wald, Dean Yale School of Nursing and others began investigating care of the terminally ill.

1974 Hospice Inc. (later renamed The Connecticut Hospice) opened the first Hospice in the United States. In the next few years, several Hospices opened.

1975 First gathering of Hospice workers held in New Haven, Connecticut.

1978 First national hospice organization board of directors established. (NHPCO)

1979 Health Care Financing Administration awarded 26 Demonstration Project Grants to hospices in 16 states.

1982 Hospice Medicare Benefit enacted

1991 The Commission on the Future Structure of Veterans Health Care (Mission Commission) releases a report recommending inclusion of hospice care in the veteran's benefit package.

1993 Hospice is included as a nationally guaranteed benefit under President Clinton's health care reform proposal. Hospice is now an accepted part of the health care continuum.

2004	More than 1 million Americans with a life-limiting illness were served by the nation’s hospices in 2004, the first time the million-person mark has been crossed.
2005	National dialog on the importance of advance care planning increases as the case involving Teri Schiavo—who dies in March—escalates in the media and within public policy debates. The Diana, Princess of Wales Memorial Fund and the Franklin Mint make $3.35 million gift to promote better end-of-life care. The American Heart Association and the American College of Cardiology release new guidelines about treating heart failure that includes recommendations that hospice care education be provided early in the course of an illness.
2007	Findings of a major study out of Duke University published in *The Journal of Pain and Symptom Management* shows that hospice services save money for Medicare and bring quality care to patients and families.
2009	The number of hospice volunteers continues to grow with a record 550,000 people serving as volunteers.
2010	*We Honor Veterans*, a pioneering campaign to help improve the care Veterans receive from hospice and palliative care providers, is launched by NHPCO in collaboration with the Department of Veterans Affairs.

In 21st Century, a large part of the American population is continuing to question their “death-denying attitudes”. Acceptance of death as a natural process is often difficult and offensive. “With the hospice movement and an increased awareness in affirmation of life and death with dignity, it is possible that American attitudes of death is changing”.[1]

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[1] The Hospice Institute of the Florida Suncoast Certification Program, Hospice Institute, January 1996

Hospice Philosophy

Its essence is well-stated by Dame Cicely Saunders, the founder of modern day Hospices.

"You matter because you are you. You matter to the last moment of life, and we will do all we can, not only to help you die peacefully, but also to live until you die."

In the face of terminal illness, when there is nothing more that can be done to cure the disease, there is still much that can and needs to be done for the patient and family. Hospice is of a specialized health care program emphasizing the management of pain and other symptoms associated with terminal illness and providing care for the family as well as the patient. Hospice services are designed especially to help terminally ill patients and families face the physical, emotional, social, financial, and spiritual aspects of their lives, and the patient's death, in an atmosphere of support and acceptance. Primary emphasis is placed on maintaining a patient at home as long as that is possible.

The patient is helped to take care of unfinished business, and to bring life to a close with a sense of completion. He or she is helped to be as comfortable and as independent as possible. Surviving family members are supported and helped to "return to life."

Hospice recognizes dying as a normal process and neither hastens not postpones death. It believes that, through appropriate care and support, the person in the last stage of life can live fully and with dignity and be free of pain and other discomforts.

Hospice focuses on caring, not curing and in most cases care is provided in the patient's home. Hospice care also is provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities. Hospice services are available to patients of any age, religion, race, sexual preference, illness, national origin or ability to pay. Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations.

Core Services:

a. Registered Nurse/Hospice Aide
b. Social Work
c. Chaplain
d. Bereavement
e. Volunteer

*Medical supplies, durable medical equipment, and pharmaceuticals must be provided as needed for the palliation and management of terminal illness.

*Inpatient care must be available for symptom management and respite.

HOSPICE MEANS *HOPE*

HOPE that the patient and their family will maintain control.

HOPE that the patient can die at home, if that is desired.

HOPE that the patient will be able to live life to the fullest.

HOPE that everything possible is being done.

HOPE that the patient and family will always have someone to talk to.

HOPE that the family can say to the patient what needs to be said.

HOPE that the patient will become symptom-free and comfortable.

HOPE that the patient, with help from the Hospice Team, will maintain dignity and journey through a peaceful death.

The Dying Persons Bill of Rights

- I have the right to be treated as a living human being until I die.
- I have the right to maintain a sense of hopefulness, however changing its focus may be.
- I have the right to be cared for by those who can maintain a sense of hopefulness, however changing this might be.
- I have the right to express my feelings and emotions about my approaching death in my own way.
- I have the right to participate in decisions concerning my care.
- I have the right to expect continuing medical and nursing attention even though "sure" goals must be changed to "comfort" goals.
- I have the right not to die alone.
- I have the right to be free from pain.
- I have the right to have my questions answered honestly.
- I have the right not to be deceived.
- I have the right to have help from and for my family in accepting my death.
- I have the right to die in peace and dignity.
- I have the right to retain my individuality and not be judged for my decisions, which may be contrary to the beliefs of others.
- I have the right to discuss and enlarge my religious and/or spiritual experiences, whatever these may mean to others.
- I have the right to expect that the sanctity of the human body will be respected after death.
- I have the right to be cared for by caring, sensitive, knowledgeable people who will attempt to understand my needs and will be able to gain some satisfaction in helping me face my death.

Written at a workshop in Lansing, Michigan in 1975, organized by the Southwestern Michigan In-service Education Council, headed by Amelia J. Barbus, asst. Professor of Nursing at Wayne State University in Detroit

Hospice Team

Patient and their Family

The most important member of the team. Our focus of care is in response to their choices for comfort.

Physician

The physician of the patient's choosing is an important member of the Hospice team. This is typically a professional who knows the patient and their loved ones and provides guidance to the team.

Nurse

By understanding the illness and listening to the wants and needs, the RN will provide education and offer options to manage the illness. The nurse is the "eyes and ears" of the attending physician, and they communicate and collaborate to keep the patient and those closest to them as comfortable as possible. As "case manager", the RN coordinates other needed services.

Social Worker

The Hospice social worker provides support and counseling to the patient and their family. The social worker assists them in coping emotionally and communicating openly with the family and with the Hospice team. The social worker also provides information and resources to guide them with practical problem solving.

Chaplain

The chaplain provides spiritual support and counseling for the patient and their family. The chaplain will visit to listen, share and reflect with them about the things they find most meaningful in life and the questions about life. The chaplain supports their faith or beliefs. Along with their own clergy, the chaplain will provide support to help the patient and their family find spiritual comfort.

Hospice Aide

The hospice aide assists the patient with personal care, such as bathing, shaving, shampooing and changing linens. The hospice aide provides companionship, while keeping the environment neat and tidy and can also prepare a simple meal.

Volunteers

Volunteers share companionship with the patient and their family. They often provide respite from the constant demands of care-giving through a variety of support activities, such as sitting with the patient, listening and sharing things that they enjoy most, and helping with special requests as the need arises.

Bereavement

Bereavement counselors are available to assist loved ones as they grieve. Bereavement services offer emotional support and grief education. These may include individual counseling, support groups, periodic phone calls, visits, and written resources.

The Direct Care Volunteer

Volunteers are one of the best sources of information and an important link between the patient and the hospice office. After a patient is referred to Carroll Hospice, a home visit is made to complete an initial assessment of the needs of the patient and family by the admitting nurse. If the patient and family opt to accept volunteer services, the Volunteer Coordinator will pursue a volunteer to meet those needs.

Once the volunteer is assigned they become the special connection between the patient/family and the hospice office. The Volunteer Coordinator will need to be informed on a routine basis how the patient and family are doing. Any clinical/medical issues should be immediately reported either to the hospice office or the nurse on-call after hours. Each contact made by phone or visit must be documented on the caregiver report forms, and a record of time and mileage recorded on the corresponding flow sheet. These documents must be submitted at least once a month to the office. Communication between the volunteer and other hospice staff (i.e.: nurse, aide, social worker) is **strongly** encouraged. "Continuity of Care" is a phrase that illustrates the need for the hospice team to be working **together** to bring the patient and family comfort, dignity, and peace.

Initial Contacts

Once assigned, the volunteer will contact the patient/family within 48 hours by phone. This initial phone call allows you to introduce yourself, explain your role as a volunteer, offer to make a visit, answer any questions, if able, and to let them know you are available to them as a concerned, supportive new friend. If they are reluctant to accept your offer of a visit during this first phone call, don't give up! Offer to call again in a few days. Some families prefer strictly phone support throughout the case, while others are eager to have you visit often. Remember that each case is unique and the patient/family will guide you to where they are comfortable.

How You Can Help

Provide support, friendship, a listening ear
Your quiet presence may be enough
Offer respite time for the caregiver
Run errands
Babysit children so other family members can care for the patient
Read and/or provide music to the patient
Do light housekeeping of patient area or kitchen
Bring flowers or treats if accepted by the family
Call hospice staff when they have a question you can't answer
Offer reassurance they are not alone
Give family members an opportunity to talk with you alone/phone – give them an objective ear
Leave your personal agenda at home – your focus is the patient and family

Facing Mortality

Death Awareness Exercise
Soul Searching Questions About Your Immortality

1. What is death?

2. Is death a topic discussed openly in your family, or with your partner?

3. My greatest fear in dying is:

4. My second greatest fear is:

5. If you had control, how would you die? What Age? In what manner? Where?

6. Who would be with you at the time of your death?

7. What would you like to say for your very last words?

8. What is going to happen to your body after you are dead?

9. What will happen to you after you are dead?

10. You have been told you have 72 hours to live. What will you do with your time?

11. You have been diagnosed as terminally ill. How do you want to be cared for?

12. How do you think your family/close friends will react to your death? How would you want them to react?

13. Take a few minutes and consider what might be an appropriate service to celebrate your life after you are gone.

14. Who would you want to officiate at the memorial services? Friends, clergy, family members?

15. What do you want people to remember about you? Words of Wisdom?

16. What has the most meaning in your life?

7. One of the things that keeps us from accepting our death is our unfinished business with others. List and describe briefly the unfinished business you would like to finish before you die. Then consider how you would finish each item if you knew you were dying soon.

A Parable

Once upon a time twin boys were conceived in the same womb. Seconds, minutes, and hours passed as he two dormant lives developed. The spark of life glowed until it fanned fire with the formation of their embryonic brains. With their simple brains came feelings, perception of surroundings, of each other and of self.

When they perceived the life of the other and their own life, they knew that life was good and they laughed and rejoiced; the one saying, “Lucky are we to have been conceived and to have this world”, and the other chimed in saying,”Blessed be the mother who gave us life and each other.”

Each budded and grew arms and fingers, lean legs and stubby toes. They stretched their lungs, churned and turned in their new found world. They explored their world and in it found the life cord which gave them life from the precious mother’s blood. They sang, “How great is the love of the mother that she shared all she has with us!” And they were pleased and satisfied with their lot.

Weeks passed into months and with the advent of each new month they noticed change in each other and the change in himself. “We are changing”, said the one, “What can it mean?”

“It means”, cried the other, “that we are drawing near to birth.”

An unsettling chill crept over the two and they both feared, for they knew that birth meant leaving all their world behind.

Said the one sadly,” We must be born. It has happened to all the others who were born here.” For indeed there was evidence of life there before, as the mother had borne others.

“But might there be life after birth?” asked the other one.

“How can there be life after birth?” cried the one; “Do we not shed our life cord and also the blood tissues? And have you ever talked to one that has been born? Has anyone ever re-entered the womb after birth? NO!” He fell into despair and he moaned, “If the purpose of conception and all our growth is ended in birth, then truly life is absurd.”

Resigned to despair, the one stabbed the darkness with his unseeing eyes and as he clutched his precious life cord to his chest, he said,”If this is so, and life is absurd, then can there truly be a mother?”

“But there is a mother”, protested the other. “Who else gave us nourishment and our world?”

“Our nourishment and our world has always been here,” said the one. “And if there is a mother, where is she? Have you seen her? Does she talk to you? No! We invented the mother because it satisfied a need in us. It made us feel secure and happy.”

Thus while one raved and despaired, the other resigned himself to birth and placed his trust in the hands of the mother, and together they feared what they did not know.

Hours ached into days and days fell into weeks. And it came to pass that they were born into light. They coughed out fluid and gasped the dry air and when they were sure that they had been born, they opened their yes, seeing for the first time. They found themselves cradled in the warm love of the mother! They lay open-mouthed and awe-struck before the great beauty and truth they could not have hoped to have known.

Author Unknown

Understanding Change In Our Lives

Death is change. Life is a series of changes. It's our attitudes toward change that affect the favorable circumstances that can come through change in our lives. The following excerpts come from the book The Miracle of Change by Denise Wholey.

Categories of Change

- Loss
- Separation
- Relocation
- Change in relationship
- Change in direction
- Change in health
- Personal growth

Important Principles of Change

- Change creates fear (but the fear can be overcome)
- Change is hard (but it's doable). It is accepting loss which leads to a new, exciting beginning.
- Accept change (and enjoy it). Plan the action but not the results.
- The only person you can change is you (and nobody else).
- Change is really exchange (so go for it). We gain through change – usually better than what we lost.
- Change is possible (even if it doesn't feel like it).
- Don't attempt major change alone – do it with an ally.
- Than answer may be acceptance (and not action). Change your attitude instead.
- Change is a process (not an event). It's what you experience (even the pain) and learn along the way.

"If nothing changes – nothing changes" –Anonymous

"If there is nothing in your life to cry about, if there is nothing in your life to complain about, if there is nothing in your life to yell about, you must be out of touch. We must all feel and know the pain of humanity. The free space that God leads us into is to feel the spectrum, from great exultation and joy, to the pain of mourning and dying and suffering.... The totally free person is one who can feel all of it and not be afraid of any of it." –Fr. Richard Rohr

"Pain and suffering may be life's way of softening us up for change."

"Painful emotional symptoms tell us our lives need to change."

"We protect our security, my total sense of self. But we become freer and more secure when we change when it's called for."

–Denise Wholey "The Miracle of Change"

The Experience of Loss and Dying One Piece at a Time

Physical:

- Ability to do certain things, i.e., mobility, continence, drive car, etc.
- Home, property, personal possessions, etc.
- Health, disease, physical conditions, etc.
- Financial
- Professional/business/career/job

Mental:

- Memory
- Comprehension
- Cognitive Functioning

Social:

- Family
- Friends
- Community
- Neighborhood
- Respect

Psychological:

- Emotional stability
- Affect
- Ability to respond appropriately to what is going on around me

Spiritual:

- Faith
- Value, meaning, purpose
- Sense that God is with me and on my side

Five Top REGRETS People Reveal at End of Life

Excerpts from "Arise India Forum" Web Page

Author: Bronnie Ware, Hospice RN

"Patients questioned (by this nurse) about any regrets they had or anything they would do differently, common themes would surface. These are the most common:

1. **I wish I had the courage to live a life true to myself, not the life others expected of me.** This was the most common regret of all. When people realize that their life is almost over and look back clearly on it, it is easy to see how many dreams have gone unfulfilled. Most people had not honored even half of their dreams due to choices they had made or not made.
2. **I wish I didn't work so hard.** This came from every male patient I cared for. They missed their children's youth and their partner's companionship. Some women also spoke of this regret.
3. **I wish I had the courage to express my feelings.** Many people suppressed their feelings in order to keep peace with others. As a result, they settled for a mediocre existence [so as not to "upset the applecart"]. Many had developed illnesses possibly related to the bitterness and resentment they carried. We cannot control the actions of others. We need to speak honestly and if it hurts the relationship then it was already an unhealthy relationship.
4. **I wish I had stayed in touch with my friends.** Often patients at the very end of life were looking to reconnect with old friends. It's not always possible to reach those friends. There were many regrets about letting life get in the way of those special relationships. [It is always about love and relationships at the end of life. It's never about finances and it's not about how much stuff you have; it all comes down to those you care about]
5. **I wish I had let myself be happier.** This is a surprisingly common regret. Many did not realize until the end happiness is a choice. They stayed in their old patterns and habits because they thought it was "comfortable". Fear of change had them "pretending" they were content. They wished they had "let go", laughed and enjoyed life more."

"Life is a choice. It is your life.

Choose consciously, choose wisely, choose honestly.

Choose happiness"

Bronnie Ware, RN

Checklist of Fears of Death and Dying

The following statements refer to your own death – what are you afraid of when you confront the fact that you will die:

I AM AFRAID

1. of nothingness – the end of everything
2. of abandoning people who depend on me
3. of making those who love me unhappy
4. of not having the time to make amends for all my sins of commission and omission
5. that death will be the end of feeling and thinking
6. of losing control over what is being done to my body
7. of the pain of dying
8. of punishment after death
9. of losing those I care about
10. of being helpless and having to depend completely on others
11. of dying, because I don't know what happens after death
12. of dying before I am ready to go
13. of dying suddenly and violently
14. of taking a long time to die
15. of dying alone

Charlotte Epstein, Nursing the Dying Patient, Reston Publishing Company, Inc. 1975

You need to know how to die to know how to live.

Count Your Blessings

Love Each Other

Acknowledge Regret

Ask Forgiveness

Offer Forgiveness

Be Thankful

Maintain Hope

Look Beyond Yourself to a Higher Regard

Team
Approach

TEAM APPROACH TO THE DYING PROCESS

OVERVIEW

Direct personal support by the volunteers is an essential component of hospice care. Volunteers provide important perspectives in the interdisciplinary team plan of care and to hospice services. Hospice philosophy and service depend upon both professional and volunteer workers in fulfilling organizational, patient, and family needs. Therefore, volunteers are an essential part of the hospice team.

LEARNING OBJECTIVES

By the end of this session, participants will be able to:

1. Understand the Team Approach to hospice care.
2. Recognize members of the hospice team.
3. Understand the role of the volunteer as a member of the team.
4. Understand the purpose and format of the interdisciplinary group (IDG) meeting.
5. Know how to access team members.
6. Implement hospice procedure at the time of death.
7. Become familiar with hospice adherence to National Standards with regard to volunteer role.

This session will also include recognizing signs and symptoms of dying.

TEAM APPROACH

The Team Approach to hospice care has been an integral component of delivering comprehensive and consistent support to our patients and families. The volunteers are an important part of the team. In order to maintain an active communication with other Team members, the following procedures are used.

Team Approach

- Disciplines that comprise the hospice team: Patient/Family 1st!
  - Physician
  - Hospice Nurse
  - Nursing Aide
  - Social Worker
  - Volunteer
  - Chaplain
  - Bereavement
- All disciplines report on their cases at weekly Team (IDG) meetings. Volunteers are contacted by the Volunteer Coordinator for updates biweekly to report to Team (IDG). Emphasis is on problem-solving and any changes or concerns brought to the meeting by Team members.
- Available volunteer representatives are assigned to attend the Team (IDG) meetings held every Tuesday.
- Memorial reports on recent deaths and bereavement family reports are conducted following IDG.
- Direct Care Volunteers assigned to a case under discussion at Team are invited to share at that time, if desired.
- Direct Care Volunteers who have questions about their patients/families may follow the chain of command for reporting immediate problems (including death of a patient if volunteer is in the home). The order of contact includes:
  - During business hours, call 410-871-8000, ask for:
    - Volunteer Coordinator
    - Hospice Patient Care Coordinator
    - Available Hospice Nurse
    - Management Person
  - Non-business hours, call 410-871-8000, ask for:
    - Triage Nurse On-Call
    - Administrator On-Call

DZ 6/04

HOSPICE PROCEDURE AT TIME OF DEATH

- Family should know to call hospice, 410-871-8000 (**NOT 911)**. Hospice numbers should be kept on a sticker by the phone.
- The office or answering service will contact a hospice or triage nurse to handle contacting a nurse to come to the home to pronounce the death. Unless requested, nurses do not need to pronounce at nursing homes or facilities where RNs are in normally in attendance.
- If a volunteer is present, you need do nothing with the patient unless the family asks for assistance. If able, stay in the home until a nurse arrives.

On the nurse's arrival, she will:

- Confirm the patient has died
- Offer support to the family
- Discard the patient's controlled medications.
- Provide care to the body per family wishes (i.e. bathe, change clothes, remove catheter and/or oxygen)
- Notify funeral home when the family is ready
- Stay with the family, if needed, until the funeral home arrives

After the visit, the nurse will:

- Notify the attending physician
- Notify the case manager
- Notify the aide and hospice team
- Call equipment company to pick up equipment

If a volunteer is present at time of death, remember:

- There is no rush
- Allow family some time to grieve - encourage quiet time with patient, if desired
- When ready, offer to call the office for the family
- Determine if the family wishes you to stay until the nurse arrives

Carroll Hospice &
Carroll Home Care

Title: IDG Membership & Responsibility Policy	Effective Date: 10/07/2015
Document Owner: Laura Welty	
Approver(s): Leslie Gee	

Printed copies are for reference only. Please refer to the electronic copy for the latest version.

Policy: Carroll Hospice seeks to provide a community of care for patients and families dealing with the distress of terminal illness and designates an interdisciplinary group (IDG) who work together to meet the needs of the patient and family. The group may consist of the patient, caregiver or family member, attending physician, hospice physician, registered nurse, social worker, spiritual care coordinator, hospice aide, bereavement counselor and a volunteer. The patient's case manager, who is a registered nurse, will provide program coordination, ensure continuous assessment of each patient's and family's needs, ensure the implementation and revision of the plan of care and ensure communication between IDG and all caregivers. Each member recognizes both the value and the limitations of his/her contribution toward meeting the needs of the patient/family. The IDG will discuss the patient plan of care at minimum every 15 days. The IDG team can meet either in person or via telecommunication.

Purpose: To provide a community of care for patients and families dealing with the distress of terminal illness and designates an interdisciplinary group (IDG) who work together to meet the needs of the patient and family.

Definitions:

- NONE

Procedure/Process/Guidelines:

1. The Interdisciplinary Group will be composed of, but not limited to, the following disciplines:
   - Medical Director or Designee
   - Registered Nurses/Licensed Practical Nurses
   - Clinical Social Worker
   - Pastoral or Spiritual Counselor
2. Additional members may include:
   - The patient's family
   - Physical Therapist/Occupational Therapy/Speech Language Pathology
   - Hospice Aides

- Dietitian
- Volunteers
- Bereavement staff
- Attending Physician if any
- Other persons involved in providing care to the patient/family
- Others, as approved by the Manager of Hospice Services
- Pharmacist

3. Ongoing review of the plan of care must occur at minimum every 15 days and/or as frequently as patient's condition requires and includes:
   a) Information from the updated comprehensive assessment.
   b) Information and changes regarding the progress toward achieving specified outcomes and goals.
   c) Communication regarding the IDG discussions and recommendation will be completed by the Case Manager

NOTE: IDG Documentation is to be completed in the Horizon system within 24 hours of the Interdisciplinary Group (IDG) meeting

4. Coordination of services:
   a) Develop and maintain a system of communication and integration
   b) Ensure the IDG maintains responsibility for directing, coordinating, and supervising the care and services provided
   c) Care and services are provided in accordance with the plan of care
   d) Care and services are based on assessments of the patient and family needs
   e) Sharing information between all disciplines providing care and services, in all settings, whether provided directly or by facility staff.
   f) Coordination with the Attending Physician

References:

A. NONE

Inpatient Care

Inpatient Hospice

When patients need a level of care that can't be offered at home

- Family Circumstances
- Treatment requirements

Inpatient Hospice

- The comforts of home
  - Rooms comfortably furnished
  - Encouraged to bring favorite things
- Medical, spiritual and emotional needs are met
- No restrictions to visiting hours
- Family/loved ones can spend the night

Inpatient Hospice

- Specialized in the treatment of patients
  - Temporary
  - Care in response to a crisis
- Return to home or to a living facility

CERTIFY

Hospice

- Presence of terminal diagnosis
- Prognosis of 6 months or less

Inpatient Hospice

- Symptoms that cannot be managed in another level of care.
- Imminent death

Dove House Code of Conduct:

- Dove House is a place of work and is also a "sacred" place. We expect the staff AND volunteers to show professionalism and courtesy in all areas of appearance and interaction.
- Dress is comfortable and casual but no jeans, shorts or tee shirts with writing other than hospice logo.
- Please do not text or phone in patient's room or in general visitor areas – go outside if you must.
- Be mindful of "teasing" comments to staff/family/patient's that may be interpreted as inappropriate.
- Watch comments made about specific patients within hearing of people around you. Patient details, even among volunteers and staff, is on a need-to- know basis.
- Volunteers are expected to complete their shift time unless previous arrangements made with volunteer coordinator. If secretary or RN determine you are not needed, or you have a personal emergency you may leave.
- Do not set out more food or make more sandwiches unless requested by staff. Freshness is a consideration. The dieticians plan the amount of food to be used as appropriate to the number of visitors in Dove House.
- Please be sure personal items are removed from volunteer desk when your shift is over.
- If you are not needed to help either with patients/family/kitchen, please remember you may be needed later on during your shift. Your availability is what matters.

Dove House Volunteer Guidelines and Code of Conduct

- Enter building by administrative office entrance during business hours. Evenings and weekends you can use Dove House entrance. You may need to use intercom for access after hours.
- Wear Hospice ID badge at all times
- Sign in and out in Blue Binder found in volunteer desk drawer
- Check in with RN on duty or secretary to determine patient/family needs
- It is appropriate for volunteers to assist clinical staff when caring for a patient. (ex: changing linens, assist with bathing, applying lotion, assist with transfers)
- Do not hesitate to interact with patients and families unless there are infection precautions or clinical staff instructs not to disturb.
- Volunteers are NOT to sign-off for ambulance transfers. Get a staff member to assist you.
    - Volunteers are **not** to feed patients, nor help with any personal care that may bring you in to contact with body fluids.
- Therapeutic musicians are encouraged to play at any time with patient/family permission. Actively dying patients are especially responsive to music when they are transitioning.
- The piano in the living room may be utilized by any experienced player. Please use the soft pedal.
- Do not linger behind nurse's station. This area is for staff only.
- REMEMBER CONFIDENTIALITY
- Keep voices lowered –acoustics in house are loud
- Wash hands before and after visiting patient rooms—infection control is paramount
- Volunteers providing bedside presence are important for patient/family comfort and safety concerns. Relax and quiet your mind. This can become a spiritual "soul to soul" experience.
- Offer tour of Dove House to families if staff member unavailable Community tours are only to be conducted by hospice staff.
- Family room can be utilized with TV/DVD's and toys for children. Instruct parents to supervise young children as some games have small pieces.
- Soothing CD's are available at the nurses station for patient rooms
- Area restaurant menus and directions can be found at the secretary's desk.
- Evening volunteers are asked to be sure all food stuffs in the kitchen are covered at end of shift.

- If you are meeting someone at Dove House, please do so downstairs in the administrative offices.
- Only scheduled volunteers should be in Dove House without special permission. Exception are home/facility volunteers who's patient was transferred to Dove House.
- You may inform an arriving family member that their loved one has died if a staff person is unavailable. Take to room, if desired, and offer emotional support. Inform staff of their arrival when appropriate.
- Some patients may develop symptoms in their last hours that are disconcerting. Vocalizations or involuntary respiratory sounds may mimic pain or discomfort. Always alert the RN on duty, but be aware that many times these sounds are NOT indicators of discomfort. It is also true that getting a patient from a pain scale of 10 to 3 (rather than the ideal 0) is the best that can be done in some cases. Our nurses are experts at pain and symptom control. We must trust that the nurses will treat (or not) depending on the real clinical picture. If you have any concerns, contact the Volunteer Coordinator.
- "The Volunteer Experience" is a support meeting for Direct Care Volunteers held annually at Carroll Hospice. You are encouraged to attend and share your stories as a hospice volunteer.
- Document your volunteer hours on the monthly "Flow Sheet".
- Document *significant* interaction with patient/family in communication book found in left drawer of volunteer desk.
- If someone drops off a DONATION of anything to Dove House, please get their NAME and ADDRESS so we can acknowledge **their generosity**

  We do not accept medical supplies or equipment for donation.

Bedside Care

Emergency Situations
Choking

- Someone who cannot answer by speaking and can only nod the head has a complete airway obstruction and needs emergency help
- Abdominal Trusts **“The Heimlich Maneuver”** should be attempted

NOTE: The American Red Cross guidelines include five back blows on conscious adults prior to administering abdominal thrusts. The American Heart Association recommends initiating Abdominal thrusts first . These two main certifying bodies differ on the initial treatment of choking victims.

Emergency Situations
Choking

How to perform abdominal thrusts

- Lean the person forward slightly and stand behind him or her. Make a fist with one hand. Put your arms around the person and grasp your fist with your other hand in the midline just below the ribs. Make a quick, hard movement inward and upward in an attempt to assist the person in coughing up the object. This maneuver should be repeated until the person is able to breathe or loses consciousness

Abdominal Thrusts

1. lean the person forward slightly and stand behind him or her.

© MedicineNet, Inc

2. Make a fist with one hand.

3. Put your arms around the person and grasp your fist with your other hand near the top of the stomach, just below the center of the rib cage.

4. Make a quick, hard movement, inward and upward.

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Emergency Situations
Severe Bleeding

- SAFETY FIRST- Please use GLOVES!
- Apply moderate pressure
- Dove House- Use dark towels- minimizes the sight of blood for family
- Report event and source of bleeding

Emergency Situations
Seizures

- Remain calm
- DO NOT place object/tongue depressor in mouth!
- Ensure patients safety- remove hazardous items
- Notify Hospice and report length of seizure activity if known

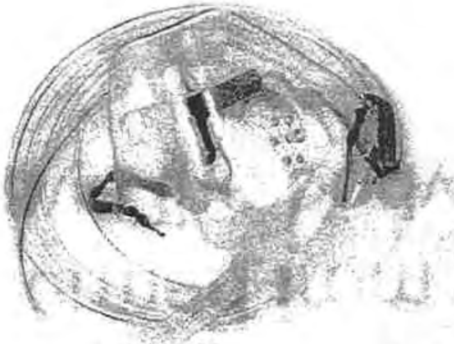
Equipment and Medical Procedures

Oxygen- Patients may need supplemental therapy. Equipment you may see in the home:

- Portable or Cylinder Tanks
- Nasal Cannula
- Masks
- Humidity- condensation may collect in tube

NEVER change the oxygen settings!

Oxygen Equipment



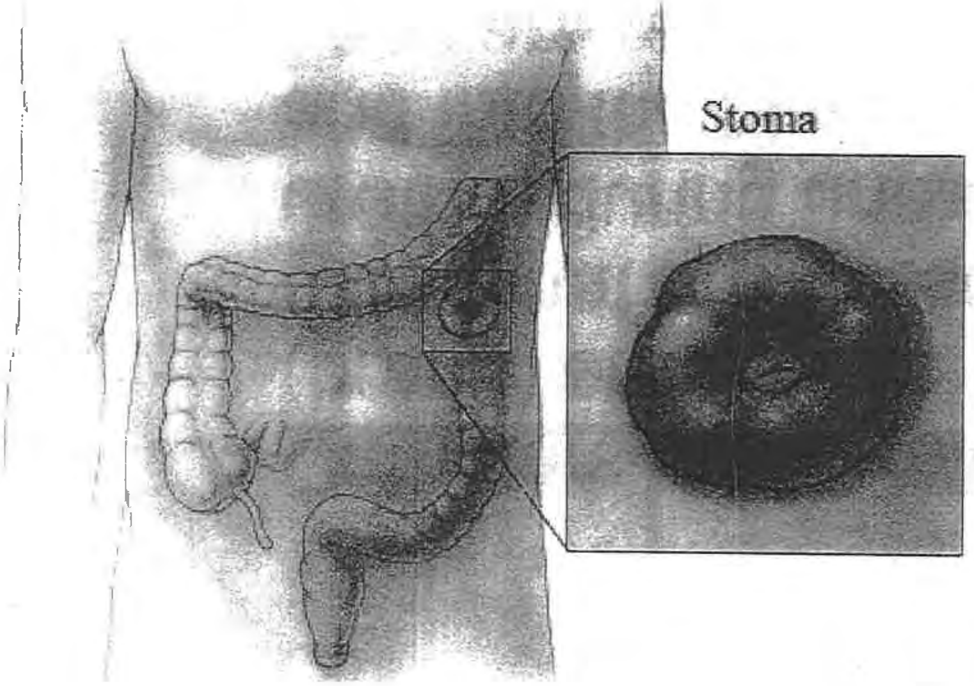
Equipment and Medical Procedures

Colostomy

- A colostomy is a surgical procedure that involves connecting a part of the colon to the anterior abdominal wall. The patient has an opening called a stoma. The stoma is formed from the intestine. Stool will leave the body from the stoma.

Equipment and Medical Procedures
Colostomy

Stoma



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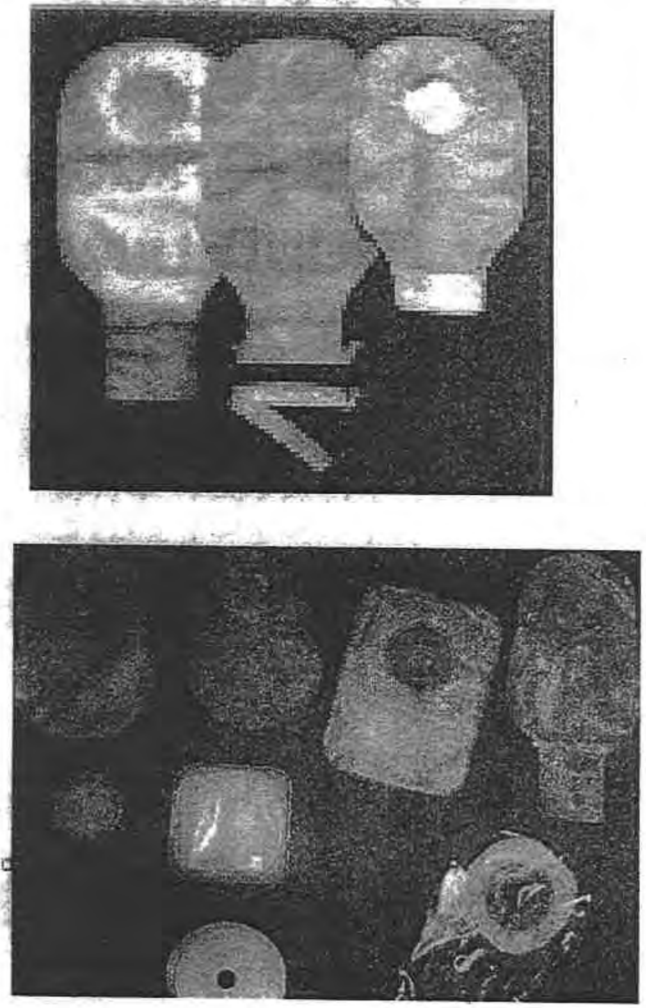
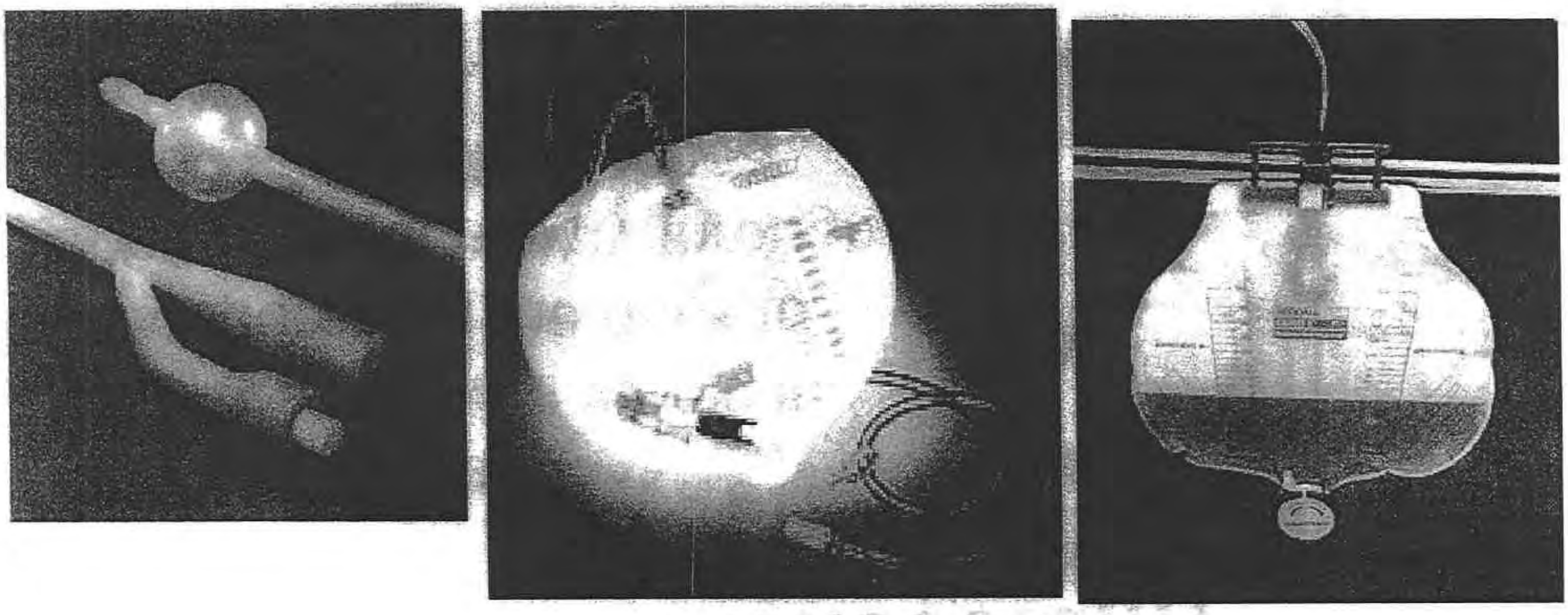
Ostomy Supplies



Equipment and Medical Procedures
Urinary Catheter

- <u>Catheters</u>- often referred to as “Foley” (brand) are flexible (usually latex) tubes that are passed through the urethra during urinary cathetrization and into the bladder to drain urine. They are retained by means of a balloon at the tip which is inflated with sterile water. There is a drainage bag attached that will collect the urine.

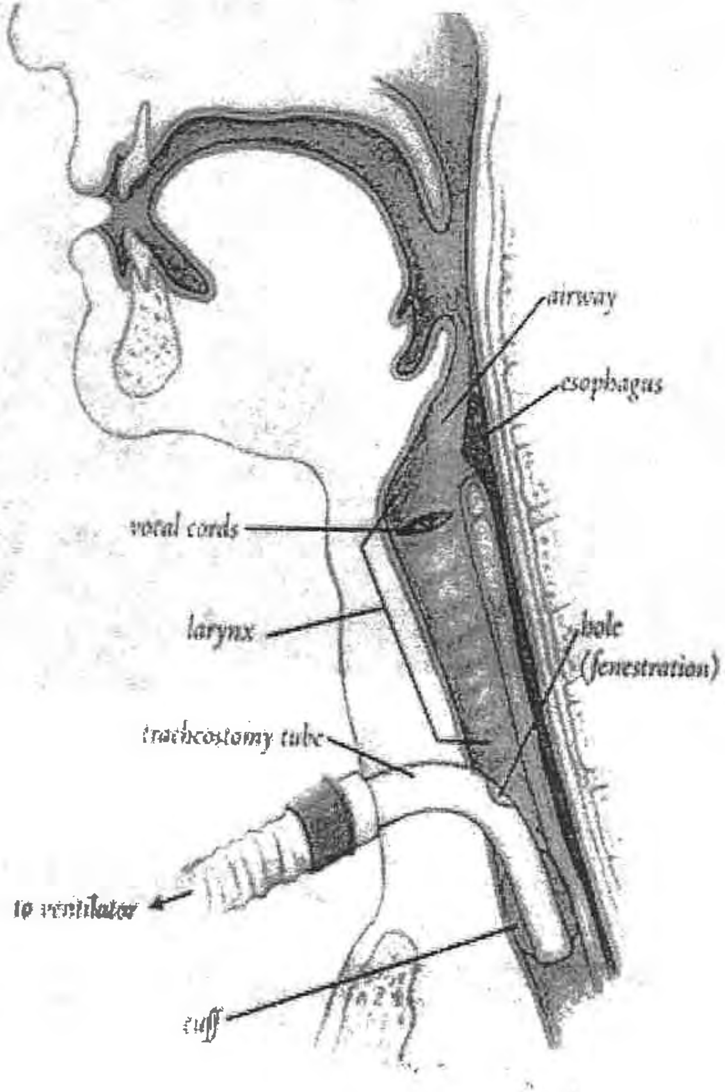
Equipment and Medical Procedures
Urinary Catheter



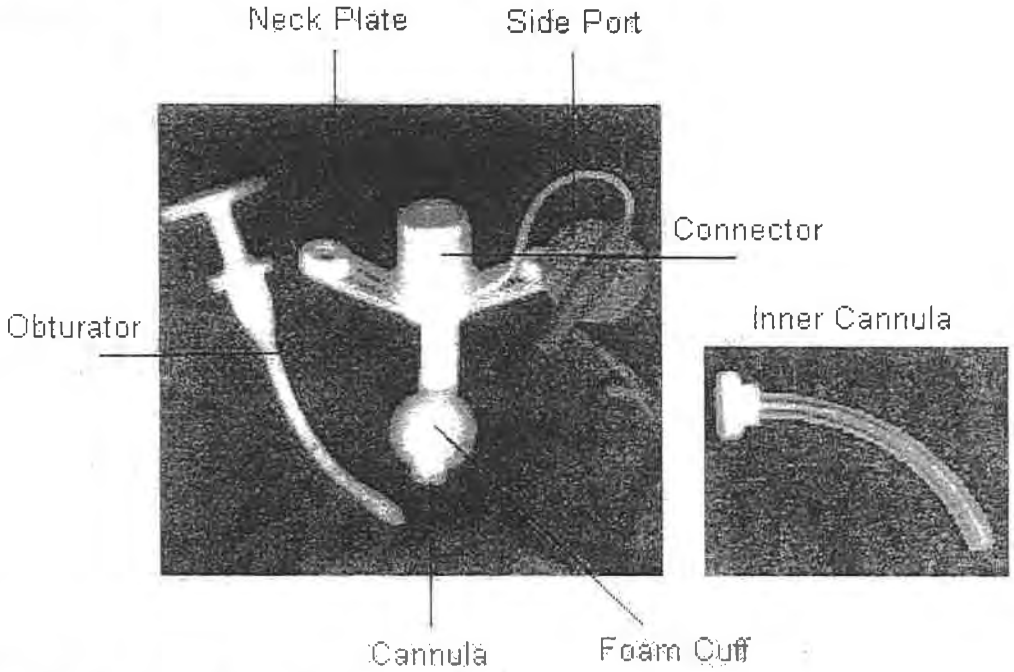
Equipment and Medical Procedures

Tracheostomy

Tracheotomy and tracheostomy are surgical procedures on the neck to open a direct airway through an incision in the trachea (the windpipe).



Equipment and Medical Procedures
Tracheostomy Supplies



Nutrition and Hydration

- Food is a fuel that helps sustain life
- As the digestive system gets weaker, food may become more of a discomfort than an enjoyment
- Some medications may change the tastes of food
- The energy requir[redacted] the food becomes greater than the energy derived it
- Leads to a loss of appetite.

Patient Care

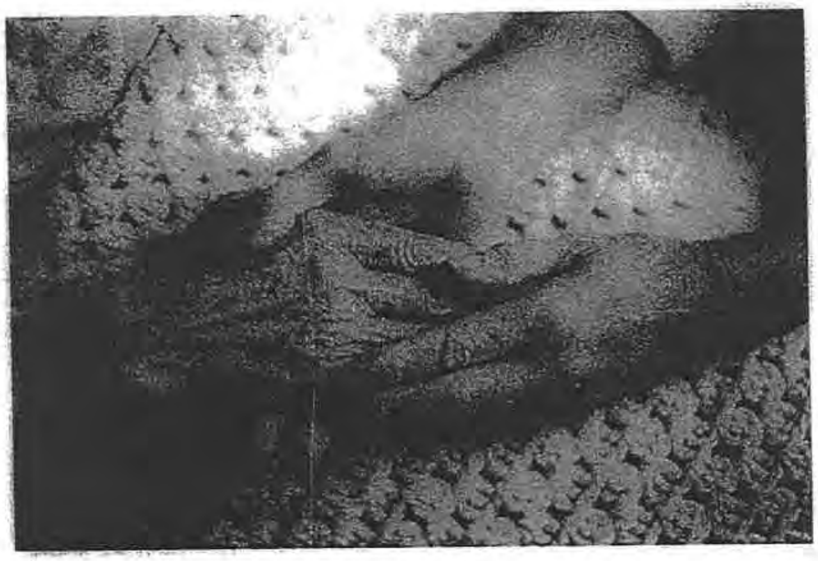
- The volunteer is not expected to provide 'personal care'. hired to [illegible]
- Communicate the task you will be performing to the patient
- Provide simple, clear directions
- When turning a patient you may want to gently rub back, apply lotion -if not contraindicated
- Maintain patient's privacy- cover any exposed areas with a towel, blanket. This will also provide warmth.

Patient Care
Mouthcare

- Mouth care is important for comfort and dignity.
- Gently swab- may use a “toothette”. May dilute mouthwash in water (Pt may suck on the swab).
- Chapstick or lip ointment may be used for comfort.

Thank You

"What I have learned over the years in sitting with the dying is that it is never too late to begin a friendship."



When Autumn Comes: A Hospice Volunteer's stories of Dying, Healing and Companionship

By: Mary Jo Bennett

Family Dynamics

FAMILY DYNAMICS

OVERVIEW

Hospice care includes the family who are caregivers as well as care receivers. This session considers the family unit structure and the changing roles with the family system through various life stages.

LEARNING OBJECTIVES

By the end of this session the participants will be able to:

1. Describe the family life cycle stages.
2. Contrast characteristics and roles of functional vs. dysfunctional families.
3. Describe varied care responsibilities in different family structures.
4. Recognize importance of understanding variance in family roles, rules, and values.
5. Identify appropriate ways to help families during terminal illness and following death.

The Family and Grief

Family members differ in their response to death which not only affects but also is influenced by the family hierarchy. Elements of family rivalry and competition can distort natural expression of feelings. Also, some members may feel "up" while others are "down", which may create an atmosphere of misunderstanding and/or tension. One or more of the following themes may be in operation, too.

SCAPEGOATING: This is a process of singling out one person or group to bear the brunt of the family's dissatisfaction. This can occur in varying degrees from simply displacing anger from the terminally ill onto the physician or nurse, to a full blown process lasting years. If a family member has been chosen, this can be destructive since the victim may believe that she/he caused the death, is a bad person, and/or needs to be punished. For example, if a child has died another sibling(s) may receive the message "why are you alive when your brother died" or "you are not wanted."

CONSPIRACY OF SILENCE: No one wants to talk about **IT** - **IT** being the death, the dying, and survivor issues. Not only are family members culturally conditioned not to talk about such subjects, but also they may be afraid of emotion reactions like tears or anger. Consequently, avoidance seems more helpful. In addition, they may be frightened or concerned about how others will react to their own expressions of feelings and opinions. This conspiracy of silence may last for a short time or go on for years; it is very destructive since it leaves members feeling alone, isolated, and guilty and therefore, the silence needs to be broken. A conspiracy of silence is usually an umbrella issue which constitutes denial but it is also a cover for anger and other emotions.

DETACHMENT: Family members pull away from each other in their grieving. This may last for a little while to forever. This is a normal reaction to loss if it is not lengthy; an individual cannot support others when he/she is suffering. This can be upsetting to family members. The reasons for this detachment are the following:

1. The initial shock of the death may make the person introspective and unresponsive to others.
2. He is protecting himself and/or loved ones with whom he/she thinks the topic may be too painful to discuss.
3. Person's own pain is so great that he doesn't have the energy to be supportive.
4. People grieve at different times and ways. There are expectations that another is not grieving enough.
5. They may be testing others to see if they will go away and leave them.
6. The detachment may be the result of a marriage or relationship that had been unstable before the death that triggered the response.

GUILT: Experiencing the normal "if onlys" of grief, the family is a constellation of each member's guilt (real or imagined) besides dealing with collective existential issues of; why did we survive, why are we being punished, and what did we do wrong to deserve this?

FAMILY DYNAMICS

HELP!
What YOU Can Do To Help

1. Establish a personal relationship with involved family members.
2. **ALWAYS** include the children. Educate the adults about the children's need to be helpful, to be included, and to be informed if age appropriate.
3. Identify friends/co-workers whose involvement may be meaningful for the patient/family and encourage family to **let** them help.
4. Inform supervisor or social worker of "estranged" family that may be crucial for contact with patient if desired.
5. Be open to sharing your knowledge about hospice care and encourage patient/family to ask questions of the other team members for answers you don't have.
6. Encourage families to take things one step at a time.
7. Encourage free expression of feelings and emotions.
8. Remind caregivers and family members they are grieving for themselves and the family unit as well as for the patient.
9. Encourage family members to share their honest feelings with the patient about remembering the patient after they are gone and what they really mean to them.
10. Facilitate frequent "time outs" or respite periods for the caregiver.
11. Help the patient to have some alone time, too.
12. Normalize feelings, emotions, fears, and thoughts for the family. All of these are valid for the individual.
13. Establish/maintain routines within the family, if possible.
14. Encourage pre-arrangements for funeral and legal consultation as appropriate.
15. Be an advocate for the patient in dealing with extended family, physicians, etc.
16. Be a confidant for the patient.
17. Provide helpful hints through your own experience/information but don't make it about you.

FAMILY DYNAMICS

FAMILY ASSESSMENT AIDS

VARIABLES TO BE ASSESSED:

personality, sex, age, maturity, intelligence, mental health, lifestyle, coping styles and abilities, religion, philosophy of life, social, cultural, and ethnic background,

AND especially -
- previous experience with loss and death
- characteristics of relationship with dying person
- amount of unfinished business with dying person
- specific fears about dying and death
- expectations about illness and death
- knowledge of illness
- personal meaning of specific illness

FAMILY CONSTELLATION

- makeup of family
- developmental stage of family
- subsystems within family
- specific roles of family members and appropriateness of these roles

VARIABLES FACILITATING EFFECTIVE FAMILY COPING

- open, direct communication
- family participation in patient care
- open, emotional support
- flexible family rules
- awareness and empathy in relationships
- flexible boundaries
- flexible relationships
- involvement in/contact with community resources
- shared power/group decision-making
- high degree of family autonomy

Source: Grief, Dying, and Death: Clinical Interventions for Caregivers by Therese A. Rando

FAMILY DYNAMICS

Family Coping Tasks

1. Denial versus acceptance of illness
2. Establishing relationships with caregivers
3. Meeting the needs of the dying person
4. Maintaining functional equilibrium
5. Regulating affect
6. Negotiating extra-familial relationships
7. Coping with post-death phase

EVALUATING COPING MECHANISMS

- Are they expectable and appropriate at this time?
- Do they safeguard the individual against incapacitating anxiety and depression?
- Do they enable the individual to maintain need fulfilling relationships with the patient and other family members?
- Do they interfere with the medical care of the patient?

Source: Grief, Dying, and Death: Clinical Interventions for Caregivers by Therese A. Rando

WORDS TO TRY

For families talking with a seriously ill person

When you think you want to say:	Try this instead:
Dad, you are going to be just fine.	Dad, are there some things that worry you?
Don't talk like that. You can beat this.	It must be hard to come terms with all this.
I can't see how anyone can help.	We will be there for you, always.
I just can't talk about this anymore.	I am feeling overwhelmed right now. Can we take this up later tonight?
What do doctors know? You might live forever.	Do you think the doctors are right? How does it seem to you?
Please don't give up. I need you here.	I need you here. I will miss you terribly. But I will get through it somehow.
There has to be something more to do.	Have we done all that is medically possible? If so, then now we get the best care we can.
Don't be sad. You'll feel better soon.	It must be hard. Can I sit with you awhile?

TABLE 4-1. THE STAGES OF THE FAMILY LIFE CYCLE

Family life cycle stage	Emotional process of transition: Key principles	Changes in family status required to proceed developmentally
Between families -- the unattached young adult	Accepting parent-offspring separation	a. Differentiation of self in relation to family of origin b. Development of intimate peer relationships c. Establishment of self in work
The joining of families through marriage the newly married couple	Commitment to new system	a. Formation of marital system b. Realignment of relationships with extended families and friends to include spouse
The family with young children	Accepting new members into the system	a. Adjusting marital system to make space of child(ren) b. Taking on parenting roles c. Realignment of relationship with extended family to include parenting and grandparenting roles
The family with adolescents	Increasing flexibility of family boundaries to include children's independence	a. Shifting of parent-child relationships to permit adolescent to move in and out of system b. Refocus on midlife marital and career issues c. Beginning shift toward concerns for older generation
Launching children and moving on	Accepting a multitude of exits from and entries into the family system	a. Renegotiation of marital system as a dyad b. Development of adult to adult relationships between grown children and their parents c. Realignment of relationships to include in-laws and grandchildren d. Dealing with disabilities and death of parents (grandparents)
The family in later life	Accepting the shifting of generational roles	a. Maintaining own and/or couple functioning and interests in face of physiological decline, exploration of new familial and social role options. b. Support for a more central role for middle generation c. Making room in the system for the wisdom and experience of the elderly, supporting the older generation without over functioning for them. d. Dealing with loss of spouse, siblings, and other peers and preparation for own death/ life review and integration

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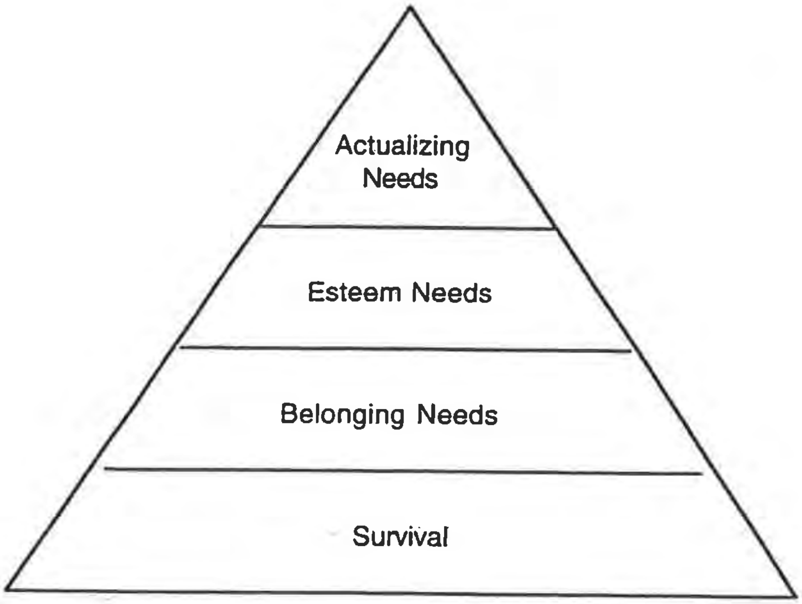
EXPLORING HELPING ROLES WITHIN MASLOW'S HIERARCHY OF NEEDS

Alan Wolfelt, Ph.D.



Survival: (Death impacts safety and security.)
To explore the impact of death on safety and security.
To assist in meeting basic biological, emotional needs.

Belonging Needs: (Death impacts belonging.)
To explore the impact of death on belonging. To assist re-establishment so that everyone still has a place in this changed family system.

Esteem Needs: (Death impacts esteem, identity.)
To explore the impact of death on individual family esteem and identity; to assist in reconstruction of a "new identity" that acknowledges changes in individual and group identity.

Actualizing Needs: (Death neutralizes growth desires.)
To explore the impact of death on individual and family growth; to assist in the re-introduction of growth desires for the individual and group (family).

The OPEN vs. CLOSED Bereaved Family:
Observed Realities

Characteristics of a Family:

1. Members of a family are interacting components,

2. Each member is a unique component of the family,

3. Each member has specific functions/roles not filled by anyone else in the family, and

4. The coordinated interaction of the members makes for a whole greater than the sum of its parts.

Characteristics of the "Healthy," "Open" Family

We should note that the term "healthy," like "pathological," carries certain connotations and should not be used as a fixed label. For our purposes **"healthy"** can be defined as a behavioral and developmental phenomenon characterized by ways of coping with situations in life (death loss), ways of moving toward life goals, and ways of mobilizing strengths and resources. When I think of a "healthy" family response to bereavement, I think of a family's capacity to openly, honestly acknowledge the death, embrace the pain, seek support both within and outside the family, and to work to discover how the death changes them individually and as a family.

Those families that bring characteristics of a "healthy, "open," family to bereavement experiences are thought to be more likely to respond in ways that result in reconciliation to the death. Those families that bring characteristics of an "unhealthy" or "closed" family to bereavement experiences are thought to be more likely to respond in ways that deny, repress, or avoid the need to mourn. A primary helping role of family-oriented bereavement counselor can be seen as that of converting the "closed" system of characteristics of denial, repression, and avoidance into more "open" system characteristics that encourage honest mourning.

Interestingly enough, the "open" bereaved family is often motivated to increase its knowledge surrounding grief and mourning, whereas, a "closed" bereaved family continues its known pattern of avoiding knowledge about what they are experiencing and demonstrates difficulty in seeking and accepting support.

As we explore the following characteristics of a "healthy" family, give thought to both your family of origin and your present family.

1. Flexibility of Rules/Roles Relationships

2. Personal Autonomy of "Individuation"

3. A High Degree of Involvement Within and Without the Family

4. Open and Honest Communication

5. Warm, Caring, Supportive Environment

6. Growth Enhancement

FAMILY LIVING STYLES

CLOSED ←——————————→ **OPEN**

Areas of Functioning	**Closed Style**	**Open Style**
Basic Family System	Authoritarian Suppressive	Democratic Flexible Nurturing Family members treated as persons
Emotional Atmosphere	Tense, Tight, Defensive, Negative	Comfortable, Warm, Trusting, Loving
Thoughts, Beliefs, and Values	Rigidly held ideas and values "untouchable"	Free, Wide-ranging, Open discussion, No untouchable area
Family Communication Patterns	Ineffective Poor listening skills	Effective Open, Clear
Family Decision Making Patterns	One member overrides wishes or preferences of others	Free Open negotiation
Role in the Family	Stereotyped, Unequal Resistant to change	Flexible roles
Family Rules	Covert, rigid Out of date	Flexible and changing Meets individual needs

PATIENT/FAMILY PATTERNS

PATTERN	FAMILY ASSUMPTION	STAFF ASSUMPTION	CORRECT ASSUMPTION
Dependency	"We always need someone stronger to lean on."	"They can't do without us."	Good at getting people to help.
Anger	"We are out of control and must take action to regain it."	"They think they do not need anyone." or "They do not want help from me."	"They feel out of control and need help to regain it."
Denial	"We are fragile and we cannot deal with pain."	"They are fragile and I must protect them."	"They are very strong and there is nothing I can do to harm them."

What to Do:

Dependent Families

- Teach them to do what they are willing to learn.
- Have **them** find additional help.
- Set limits for yourself.
- Explain those limits to the family.

Angry Families

- Give them decisions to make.
- Keep informed and consult.
- Teach them to do more for themselves.
- Praise them for their competence.
- Reassure them you want them to be in charge.
- Set limits - refuse to take abuse.

Denial Families

- Begin with what they will admit.
- Use "just in case" scenarios.
- Use strong, direct language in matter of fact tone.
- Understand it is not your mission to break through the denial process.

Tensions For Families

You will often find your family torn by emotions. People deal with tension in all sorts of way, but it often helps just to be able to name the problem. Note that the best "place" to be is not usually at one end or the other, but somewhere in between.

Hope ↔ Despair

Denial ↔ Acceptance

Meaningless ↔ Meaningfulness

Independence ↔ Accepting dependency

Family burden ↔ Opportunity to serve

Ambiguity ↔ Certainty of outcome

Making plans ↔ Experiencing emotions

Holding on ↔ Letting go

Speaking openly ↔ Not talking

Family as it was ↔ Family as it is becoming

Closed Family Systems

Closed family systems have very rigid boundaries, making it very difficult for family members to have contact/relationships outside the nuclear family (reaching out) and making it very difficult for persons outside the family to make contact with family members (reaching in). Open systems have very permeable boundaries, allowing both family members and outsiders easy transactions across the boundary. The relative openness or closure of the family system is usually determined by the father and/or mother. They, in essence, determine who will have contact inside or outside the system, and under what conditions.

The relative openness or closure of the family system will influence:

* the family's ability to provide care and emotional support to the dying member,

* the ability of the family to adjust to the changes precipitated by the death of the family member, and

* the family's willingness to accept help and support from anyone outside the family.

Of the family typologies presented, the closed system described by Satir has a high potential for family disruption and the emotional dysfunction of individuals precipitated by illness and death of a family member. The isolation of family members, the rigid resistance to change, and the communication problems in these families makes the experience of death extremely disruptive to individuals and the family system as a whole.

Family Rules

Satir (1967, 1972) has explored the nature of both the spoken and unspoken rules that govern family life. Each family has its own unique rules that govern how we act, what we feel, what we can express, and what kind of relationships we can have with others. Such rules have often been passed down from generation to generation, and have not been examined for their origin or for their current utility to the family. Family rules may cover many diverse aspects of individual and family life. Examples of family rules might include:

Don't raise your voice.
Make others happy.
Men cannot be trusted.
Daddy works hard. His needs are more important than ours.
You can be anything you want to be.
Go to college.
Don't talk about __________'s illness.
Anger and hate are the same thing.
If you aren't careful, you'll end up just like ...
Sex...don't talk about it or enjoy it: if we're quiet maybe, it will go away.
Children must be protected from painful experiences.
Don't cry or I'll give you something to cry about.
Marry early (or late).
Feelings are important.
We can work it out.
You should be ashamed of yourself.
To ask for what I want is selfish.
Take care of everybody.
Never make mistakes.
Everybody must agree.
We know what's best for you.
You are a special person.
Stay married at all costs.

In healthy families, rules are openly stated and negotiable. In troubled families, rules governing behavior are often more hidden, and there are prohibitions against making such rules explicit or trying to negotiate them.

As the hospice volunteer works with dying patients and their families, a number of family rules may pose obstacles to the resolution of grief and the restabilization of the family following the death. Such rules may include proscriptions for family member roles, specific roles the appropriate response to death, and more general rules governing the expression of emotion within the family. Can you identify rules you have observed in families that posed major difficulties in the family's adjustment to the death of a family member?

Family Roles

Each family member may have many roles within the family. For example, a woman may fulfill such roles as mother, wife, career woman, disciplinarian, pal, peacemaker, etc.

The development of roles is an ongoing process throughout our lives. Our own personal growth and changes within our families require taking on new and different roles. In healthy families, roles are highly flexible and one member may take on the roles of another, For example, a mother may take on the roles of the father who is injured, ill, or not able to perform his normal functions in the family. In troubled families, roles are highly rigid and members have great difficulty interchanging roles or taking over the roles of a family member who for whatever reason, cannot continue to perform his or her role functions.

An understanding of family roles is very important to the hospice volunteer. First, the roles performed by the dying patient in the family and the family's ability to absorb these roles by other family members have a profound impact upon the family's overall response to the patient's death. Second, the bereavement volunteer can play an important part in helping families redefine roles following the death of a family member.

Excerpted from The Anatomy of Bereavement by Beverley Raphael. This excerpt recalls a young woman's grief over the death of her husband and young daughter.

Annie is thirty. Her hair is softly curled. Her dark eyes are quiet and sad.

"Well, John and I are managing. We are just managing. I thought we never would. In those early months it was so hard for him. I was so wrapped up in my own grief, in my own feelings, that I hardly noticed him at all some days. Then one day I looked at him, and I was shocked. He was quiet and thin and withdrawn - not himself at all. That pulled me out of things, it really did. He'd needed me, and somehow I'd been away from him - elsewhere, I suppose. It was as though I was expecting him to look after himself, maybe even to look after me. I know I used to say to him, 'Hold Mummy, John, hold Mummy, that'll make you feel better,' but perhaps it was just for me.

So I put my sorrow aside for a while, I wasn't over it by any means, and I made John my life, my whole life, I cuddled him and loved him. I spent my days with him. And he started to respond. He came back, slowly at first, but he came back to his old cheerful self. It all gave me a terrible shock, really, as though I'd let him go and I'd lose him too.

We started to pick up the reins again then and think about what we would do with our lives. We could manage on Pete's insurance, but not with the standard of living we'd had before, I thought of going back to teaching. John could go to kindergarten; he'd like that with some friends. It would take his mind off Lissa. Then I thought, it was so long since I had taught, what if I wasn't any good any more? There would be so much to catch up to, so much to learn again - I didn't know if I could do it.

It was like so many things in life - I'd been Pete's wife and Melissa's mother, and John's too, of course. I felt as though I'd been those things forever, and now I wasn't them anymore - so who was I? I was Annie, alright. But Annie had been different; she was the popular girl at school, the smart young schoolteacher - but not the woman. The woman had been with Peter and with Melissa. And this Annie woman without them, well, I didn't know her at all; I wasn't sure who she was. There were so many ways in which I felt strange, different, not myself. Being a single mother, just one child, no husband, no daughter. Filling out forms brought all that home; all the spaces and headings and explanations and red tape that I'd never noticed before. My old friends, too- they changed as well. They were uncomfortable, just uncomfortable about me now - a woman without a husband. Some of them stopped asking me over, as if they were afraid of what woman without a husband meant. Maybe they thought I'd take theirs. Some would ask me over and ask a conspicuous extra man: 'What do you do about that?' I would ask myself. Should I start to be interested again, even if I didn't feel like it. Anyway, how can you start again on all that old business of seeing if they like you, wondering if you like them, dating, whatever? That's for teenagers, not for women.

Now the year has come and gone since his death, since Melissa died. We are finding our feet. We go out. I work. You could say I'm doing reasonably well. John and I have our own small quiet world. It's a little family. But we are a family again."

A Goal for the Dying: Care of the Living

by Taschia Ann

Yesterday, I went to look at a Hospice care unit for the terminally ill at the Howard Young Center. This was the final step of a long series of events that started six months ago; actually it started four and a half years ago. You see, I *am* the patient for the hospice unit. I have cancer. The four and a half year fight has now consummated in the need to find a place where I can be cared for during the next and final stage.

I am writing this not so much for the families of the terminally ill, but for the persons who have to deal with this reality just as I do. There is a need for frank, clear talking among those of us who have to sort out this reality - one that states what the final goals of life are. "We" are not a part of the population that is facing old age and failing health which leads to the inevitable last step; nor are we one of those who willingly chose a path or lifestyle which will knowingly end with death. "We" are those who have contracted a disease that places us and our families in a not so rare situation today. Recent research just came out with the startling information that "... a child that is born today... one in three will contract cancer and one in five will die from this disease." I do not see much headway being made by the medical profession. Instead I see diverse groups of doctors and researchers all "doing their thing," while we sit on the sidelines hoping that someone will push the right button. Well, there are those of us that cannot wait any longer for the right button to be pushed, but we can and must go forward with the remaining time in a positive, constructive way, recognizing full well what is ahead and preparing ourselves and families and friends for the future.

I wish to clarify the term family. Today family does not only mean the blood relatives we have. It also includes friends from various aspects of our lives; neighbors, church members, professional colleagues, etc. Since our society has become so transient we often do not live near the family members that we feel closest to. Our extended family is a product of our need to feel that we belong to a close group; therefore, when I use the term family throughout this article, I am meaning the extended family. Each of us has to place in the group the people we consider we are close to.

The brief description of my past history is so common that it is not newsworthy, other than that it is too typical. In 1982 I found a lump in my breast, the surgery occurred and I found that I had cancer. After conflicting recommendations as to how to proceed, I chose a tough round of chemotherapy. This procedure lasted one year; six months of treatment and six months of recuperation. During the next year, I sailed along in my old form; teaching school and keeping a busy lifestyle. Then, just about the time I found myself relaxing, not getting nervous every time something happened, I found a new lump in my neck. This proved to be lymphatic in nature and radiation followed. No longer did I kid myself that I was going to be one of those persons that was free from the creeping disease. Again, I returned to work and my regular lifestyle. One more year passed and a regular bone scan turned up positive. The invader had found a new home and the doctors stated that now the disease was in the liver. The news that the invader had reached a vital organ brought with it the reality that I was terminally ill. This is not stated in some remorseful way, but in a factual manner which must be understood in order for the rest of this article to have real meaning to those who are going through the same experience. It is also important that you understand that I have also been in the role of "family." My mother died of cancer five years ago.

Now, when we are presented with this set of facts, how do we respond? Each of us has to go through a period of grief which includes the stages of anger, remorse, depression; and then we go slowly on to resolution. It seems that we can handle this reality better if we do not try to deal with it all at once, if we allow ourselves time to think about little parts of the whole picture before we try to look at it in its entirety. If we take steps towards resolution slowly, we can try to avoid the overpowering feeling of blame toward everyone and everything in our lives for this terrible set of circumstances: including God and heaven knows what else and who else. We have the option to take this time and USE it. Although our lives have not stopped, we can no longer complete the same kind of jobs we did before. This does not mean the end of our work. It only means that our goals have changed and we need to look at what needs to be done now. There is a new job to complete. Now is the time to go forward and deal with this final stage in our lives with dignity and caring.

A Goal for the Dying; to Help Care for the Living

1. Help your family understand your decisions.

Take a clear look at your options as to how you are going to handle that period when you no longer function effectively. You should look at those options so you can make a choice based on your needs, income, family status, and religious preference.

There are the obvious - nursing home, hospital, staying with relatives, or relatives staying with you. There is also a new concept present in many communities, the hospice. The hospice allows you to stay at home for as long as possible with the help of a person or group of persons that provide primary care. The hospice is a support system for all involved, not only medically but emotionally. I have chosen the latter. I went to the visit the hospice care unit, talked with those in charge, and looked at the facility. This was not a depressing experience but rather a relief, for I could see now, when I am still in good control, the place I wish to stay later.

I then sat my family down and explained why I picked this avenue of care, gained their understanding, and thus relieved the family of that concern, "Am I doing what she wants? Am I making the right choice?"

2. Let your family help you.

Allowing your family to help in any way they feel capable is allowing them to say to you that they care. Do not become a stoic or so independent in your bitterness or unhappiness that you turn your family away saying, "I can do it myself," or "I do not need your help." There are two very destructive things that occur when you do this. First, you shut out the family and they have no way of demonstrating how important you are to them. They can have a great deal of guilt when you have died, if they did not have an opportunity to "give" that which they had to give at a meaningful time. For months later, if not years, the old images could return, "If I had only done..." or "If I had just changed...perhaps things would have been different." Well, you and I know that things would not have been different, for the timetable within our bodies has made that clear. But those who stand by and watch need to have a chance to participate in a meaningful way during this final stage. Second, you have taken away the family's chance to bind together. The coming together of your family during this time is most important. When you die they will need each other for support through the grief period. So it is important that you make an effort to have the family meet each other, to be together as much as possible so that they can begin to feel comfortable talking openly together. The carry-over to later times will be invaluable.

At the same time that your family's efforts are important to you and to them, they need to be allowed to go on about their worlds without concern. Let me give an example of what I mean. Even though my two sons, ages 25 and 28, have been available to help me with many things that need to be done, I have made it clear that they need to go on about their lives. One son starts graduate school this fall, 200 miles away. My other son is off to Germany on a job-related trip for two months. It is very important that they understand I NEED to see them going forward and not become stagnant in their efforts to progress. There is not an agenda to a terminal disease. To stand by and wait is a destructive use of one's energies. But remember, your telling them to go on with their lives provides permission from you and lessens their feelings of guilt and concern.

In some instances, there can be special problem for a family member. Once the family member acknowledges and accepts the fact that you are terminally ill and are going to die, a separation starts before the time when you are no longer there in hopes that this will lessen problems later. If this behavior is misunderstood, your feelings could be hurt and once that starts it tends to feed on itself. One way to keep this from happening is to call attention to what you are seeing. Tell the person who is exhibiting this behavior what is happening and that you can understand why.

A similar behavior occurs quite often in the classroom. I teach kindergarten. Toward the end of the school year when the children realize that I will not be a major part of their lives next year, they start to make the break before school is out so they will be ready for the new teacher the next year.

3. Let your family see you continue to be constructive.

Yesterday, the doctor said to me, "Do those things that are important to you NOW, don't wait." It is necessary for you and your family that you do what is important to you. That can range from taking a trip to knitting a sweater for your grandchild. The importance for you is a feeling of completion, and for the family to see you taking this time for continuing happiness. This provides everyone with a sense of closure or completion. The fact that this time is not a time to deny yourself pleasure, is in some measure giving pleasure to the family. They see this time as being productive. The goal is to lessen regret later for things done or left undone which helps the family after you are gone.

4. Let your family be aware of your wishes for burial.

Cultural backgrounds and religious preferences become more important to you and your family as the import of your illness becomes acknowledged reality. When you and the family get past the point of denial that the illness is terminal, your background in dealing with illness and death based on your culture and religion will play a large role in your approach to the future. I do not deny that for many the integration of the prognosis of terminal illness with the way in which your family has handled deaths in the past can be very difficult. I am not sure what guidelines can be stated here, other than that it is up to you to set the tone or rules for your family. You must be honest with your family as to how you wish your death and burial to be handled. Again, here is when the family will wonder if they have completed your wishes correctly. Your goal is to lessen concern by making the arrangements beforehand. This does not leave the family with the ever present concern, "I hope I have done what he/she wanted."

I am an Episcopalian and I believe in Jesus' promise of life after death. My family does not. So, I have felt a real need to be sure that my death be taken care of correctly by the church and me. There is no doubt that the family will follow my wishes, but it is my responsibility to make those wishes clear.

5. Let your family know all the facts about your illness.

The role the doctors have played in your life has been, to some extent, the guiding factor for what you have done. They have, as they say, "called the shots" in terms of how you have dealt with the illness and this is as it should be. But, the family can begin to have real difficulty in realizing exactly what a doctor can and cannot do. I have witnessed family members who expect the doctor to be some kind of miracle worker, and when this does not occur, blame the doctor for being incompetent. Doctors are only people. They can state what they see but without a crystal ball they are no more equipped to give absolute answers than anyone else. The honesty and factual information that doctors are now required to give to the patient and family certainly improves the situation over those days, not long ago, when the majority of information was not given. However, this does not mean that the doctor can foretell all ramifications of an illness that has the potential of becoming terminal. There is great responsibility now placed upon you, the patient, not only to listen to the facts from the doctor, but to be completely honest with the doctor, not to withhold information in hopes that the symptoms "will go away." This kind of denial can cause serious problems for all involved. The family starts misreading the signals from both the doctor and you which then results in a major problem after death. The problem is that the family, going through their grief or guilt, will sometimes go back to the doctor and blame him/her for the death. It is up to us to keep this from happening when possible. There has to be clear, plain talking with the family. The more honest you are, the better for all involved. Remember, you are talking about a terminal illness. Any person involved with our life that loses sight of this fact is a person that may later wish to punish someone for their loss. That someone could be your doctor.

Our goal and responsibility in this area is great. Your must help those around you keep their objectivity as it will be essential later. Your help can be a real gift to those you love and care for.

I am sure there are areas that I have not thought of, but you will. Some areas of concern are unique to each individual. But, I do hope that the guidelines set down here will give you a course of action to follow. These guidelines should be kept foremost in your mind as you consider the days or months ahead.

I wish to make it clear that in no way is this article to convey a "giving-up attitude" or the feeling I am resigning myself to death. On the contrary, it is meant to relay what one does in acting in a positive way. I have been told all of my life that I have been a fighter for life, not a quitter. This article is not a quitter's comments but rather a continuation of life in a realistic manner. My goal is always and has always been to deal with life in a constructive manner that demonstrates a caring attitude for others. May this article help others to do the same. The terminally ill person, regardless of age or gender, knows all too well that life is precious and to be able to give a gift to another now is the final act of dignity and caring for one human being for another.

This article first appeared in the Advent 1986 edition of The Anglican Digest. Reprint permission freely granted.

Boundaries

BOUNDARIES

OVERVIEW

"Am I my patient's keeper?" This section looks at boundary issues - setting appropriate limits with the hospice team and family.

LEARNING OBJECTIVES

By the end of this session, participants will be able to:

1. Recognize the importance of understanding boundaries in hospice patient/family care.
2. Define fiduciary relationship as it applies to hospice care.
3. Identify at least 3 possible boundary violations that could occur in hospice.
4. Recognize warning signs and preventative measures.

Boundaries and You
Objectives

- Understand the provision of professional care
- Define what is and what is not appropriate behavior in the workplace
- Protect your rights and privacy
- Increase patient satisfaction with services received

Rationale for Boundaries

- The organization has established boundaries that all associated must comply with
- Patients have the right to professional care from all the staff of Carroll Home Care and Hospice
- Patient Satisfaction is compromised if an associate over-steps their boundaries
- Associate satisfaction is compromised if a patient over-steps their boundaries

Boundary Considerations

- Set boundaries – It is possible to remain compassionate without immersing yourself
- Use good judgment and common sense
- You cannot solve your patient’s problems
- Learn to say no
- Be aware of your own unfinished business

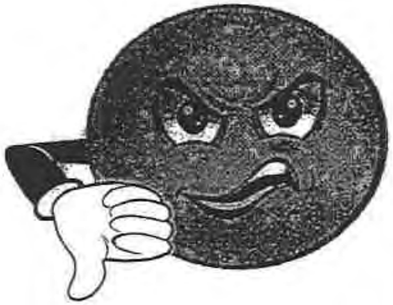
Warning signs

- Making special exceptions outside of the care plan
- Misinterpretation of the relationship with a patient
- The need to save, rescue, cure
- Sense of specialness
- Sense of entitlement
- Asking the patient or family to do something for you or the agency
- Pseudo intimacy – the need for physical or intimate gestures (kisses, gifts, etc.)

You may have overstepped your boundaries you

- Lost your objectivity
- Stress increases
- Thinking of your patient frequently
- Feel like you want to take over
- Feel like the patient is your responsibility

Guideline what not to do



- Sell items to patients or families
- Provide transportation to patients or families
- Have romantic relationships with a patient or family member
- Tolerate any type of abuse (verbal, physical, threats or sexual harassment) from a patient or family member

Continued:

- Lend money or anything else to a patient or family member
- Borrow money or anything else to a patient or family member
- Accept money or gifts from patients or family members

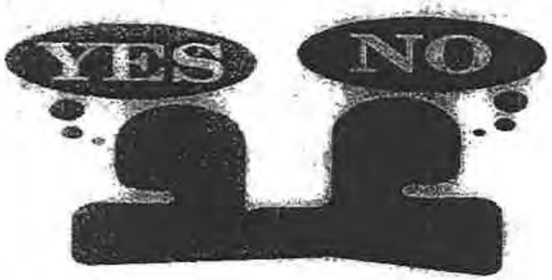
What you should do

- Always obtain supervision and/or consultation in difficult cases or situations which make you feel uncomfortable
- Remember that your actions might impact on another associate's role or relationship

Things to Consider if you are having trouble deciding if something you would like to do is in the best interest of the patient

- What is it that you would like to help the patient with?
- Do you think this is a one time request/event? Why?
- What is the main reason for wanting to help this patient? What are your intentions?
- What would a trusted co-worker or supervisor think about what you want to do for the patient?
- Assuming the patient is able, what could you do to help them do for themselves?

- After asking yourself these questions, list the positive outcomes and possible negative outcomes for this patient



Once you have considered all of this, determine

Yes, you have decided it would be helpful or

No, you have decided it would not be helpful

It’s Your Responsibility to

- Tell patients what you will be doing for them
- Set clear limits in advance about what you can and cannot do for the patient
- Balance emotions with professional judgment
- Be aware of your personal limits
- Use supervisory support
- Keep social and emotional needs away from work
- Reflect on how other staff member will interpret your behavior
- Be aware of your own comfort levels. What type of scenarios would make you uncomfortable?

Do's and Don'ts

- Do follow the care plan. Notify your supervisor if the patient is asking you to do things you are not assigned to do
- Do follow agency policies and guidelines
- Do ask for help is you are uncertain about something
- Do use your supervisor for support
- Do only things you would do if a co-worker or supervisor was present

Do's and Don'ts

- Do not give your phone number to patients (home or cell)
- Do not share personal problems or your own aches and pains with patients
- Do not talk about other patients (HIPAA)
- Do not talk about your employer negatively or about problems that may be occurring at with an employer
- Do not take criticism or verbal assault personally – discuss with your supervisor

KEEP IN MIND

- Boundaries are unique to each person and each caregiver-patient relationship
- Boundaries are not clear cut matters
- Your patient may need help to establish appropriate boundaries

Boundaries

- **Set Boundaries:** Observe the struggle and remain compassionate but don't immerse yourself.
- **Avoid thinking you can solve other peoples' problems.**
- **Be on the lookout for client/family dependency on you.**
- **Learn to say "No."**
- **Be aware of your own unfinished business...** the things you think and feel about dying, and why your own experience with death and dying could negatively affect your work with the family.
- **Remember that "unfinished business" goes beyond one's perspective on dying...** for example, imagine that your patient's husband is an alcoholic and **you** grew up in an alcoholic family... take care that your own experience with chemical dependency doesn't negatively influence your interaction with the family.
- **Avoid becoming the family therapist.** Are you being pulled in, in ways that make you feel uncomfortable? Tactfully tell them so.

I Know I'm Exceeding My Boundaries When:

- I lose objectivity... I become resentful toward a family member (even if I don't express it).
- My stress increases... I feel emotionally on edge with my own family and friends.
- I find myself thinking about the patient/family too often.
- I feel like I want to take over.
- I feel the patient is my responsibility.

Warning Signs

- Making special exceptions outside of the team or care plan
- Misrepresentation of the relationship
- Pseudo-intimacy
- Relaxation of post-termination therapy boundaries
- The need to save, cure, rescue
- Sense of "specialness"
- Sense of entitlement
- Asking clients to do something for you or the agency

Flagrant boundary violations on the part of a few may be viewed as passive approval or facilitated laxness in the collective ethical standards of the industry.

TAKING CARE OF YOURSELF

Take Time To Relax
- Deep breathe often
- Read a book
- Watch a movie
- Stretch your body
- Get a professional massage
- Hug someone for a good minute
- Listen to soothing music
- Listen to audio books in your car
- Mentally close the door on worries at night - there is little you can do after dinner!

Eat Right and Exercise
- Walk at least 3-4 times a week
- Eat fruits and vegetables - limit red meat and fried foods.
- Eat smaller portions but what you like
- Drink water all the time
- Limit caffeine - try special blend teas that are decaf
- Treat yourself to goodies occasionally - life is too short!

Be Selfish Once In A While
- Learn to say "No" - don't over extend your time or energy; too much "giving" leads to burnout and then you are unable to give anything
- Protect your private time - turn off [illegible] cell phones and ignore answering machines when you are on "your time"
- Nurture your own interests
- Protect yourself - stay aware in unsafe areas, learn self-defense
- Depend on others for help and support when your need it

Laugh A Lot

- Learn to laugh at yourself
- Don't take things too seriously, especially the "little" things. How do they compare in the grand scheme?
- Watch a comedy movie or listen to a comedy tape
- Tickle someone you love
- Smile at everyone - it will come back to you
- Smile on the phone, too
- Read the comics
- Stop in the card store and browse in the "humorous" section
- Don't be afraid to be silly, like a child - finding delight in the ridiculous is a lesson they can teach us
- Play!! - you remember how
- Laughter releases the "feel good" hormones in your body

Sing

- In the shower
- In the car
- In the family room with a candle as a microphone
- Join the choir at church
- Everyone is a singer and has music in their soul - you can be tone deaf and still enjoy singing (you can't hear if it's a wrong note anyway!")
- Singing releases emotions; relaxes your chest, throat, and facial muscles; creates an atmosphere of well-being

Feel It, Express It, Let It Go

- Let go of anger once it has been vented - deep breathe and reevaluate
- Learn to forgive - mistakes are learning tools
- Letting go of anger and offering or accepting forgiveness leads to less stress and leaves no room for guilt or regrets later
- Cry - physically and emotionally it makes you feel better

- Don’t worry so much:
  - 40% of what we worry about is in the past and we can't do anything about it
  - 30% of worries are about things that never happen
  - 20% of worries are about things that do happen but over which we have no control
  - 10% of all worries are about things we can do something about
- Accept people as they are - search for the good
- Be aware of gossip - don't perpetuate it
- Tell the special people in your life your love them
  - Write letters NOW
  - Verbally express NOW

Never Stop Educating Yourself

- Pursue education and the gathering of knowledge - it leads to a longer and more productive life; studies have found that the continual stimulation of learning may prevent dementia/Alzheimer's
- Go back to school or take a class that interests you
- Read newspapers, magazines, non-fiction and watch documentary films
- Learn with your kids

Be Creative

- Write - stories, lyrics, music, poetry, love letters, plays, nonsense, your life story; write in a personal journal
- Art - go to museums, create your own medium of expression, finger paint with the kids, make gifts/crafts
- Cooking is an art
- Rearrange your space - redecorate, move the furniture, change the pictures on the wall, light candles, buy a bright throw pillow
- Plant or work in a garden
- Fill your world with flowers, dry flowers, arrange flowers

Embrace Your Spirituality

- Ask yourself "What give me comfort and peace?"
- Choose a sacred place and use it daily for solitude and reflection
- If you are a member of a faith, attend your church regularly and learn about what it means to be in touch with your God
- Explore nature - walk in the woods, watch the sky, lay at the foot of a tree and observe the leaves in their dance
- Use music to help you relax and focus on your inner self where you can touch your spirituality
- Help others when you can; it can become a spiritual experience
- Keep an open mind to spiritual beliefs and happenings - we can find meaning for ourselves from other perspectives

Stay Active

- Get out of the house (if you're inclined to stay home)
- Get away for the weekend every few months
- Meet with old friends you haven't seen for awhile
- Be a volunteer
- Don't go to extremes with too many activities
- Set priorities - yourself, family, work, friends, community, etc.

Love Yourself

- Change what you can; accept what you can't
- Grow from your mistakes and failures; forgive yourself
- See a physician routinely
- Take time for yourself
- To love and care for others, you must first love and care for yourself

☺

Grief

GRIEF AND BEREAVEMENT

OVERVIEW

Death of someone loved may result in a variety of physical, emotional, social, familial, economic, and spiritual disruptions. Grief and bereavement are normal reactions to loss and death. Grief is a highly personal response to loss. Bereavement is the period of deprivation following the loss of someone loved. Grief is on the inside and mourning is what we show on the outside. Grieving may precede an anticipated death or may be delayed for a considerable amount of time; it is always dealt with. Grief may manifest itself in emotional and/or physical ways at different times. While some can resolve grief with time and their own resources, others require formal assistance and support over an extended period.

This session focuses on the grief of the family. The family is the focus of care for hospice and care is given to the family in the bereavement follow-up services. Carroll Hospice offers bereavement counseling and support groups to the community at large as well.

LEARNING OBJECTIVES

By the end of this session the participants will be able to:

1. Recognize normal grief responses in different stages of loss.
2. Describe actions the volunteer should and should not take in order to be most helpful to the person who is grieving.
3. Write an effective condolence note.
4. Describe hospice's bereavement and support programs.

Carroll
Hospice

BEREAVEMENT SERVICES

BEREAVEMENT SUPPORT GROUPS

Bereavement Support Groups are open to anyone in the community regardless of where the death occurred.
If the weather is inclement, please follow the Carroll County Public Schools policy. If schools are closed, our groups are cancelled.

Pathways Support Group - *No registration required - Held at Carroll Hospice, Westminster, MD*
This monthly bereavement support group is open to anyone who has lost a loved one. The group addresses the emotional issues surrounding the loss and offers coping strategies.

- Third Wednesday of each month from **6:30 PM – 8:00 PM**

Bereavement Luncheons - *No registration required* An opportunity to meet, have lunch and receive support from others in the community that are suffering from the loss of someone close. **Please call for location, 410-871-7231 or 410-871-765** • Last Tuesday of each month at Noon

Footprints Support Group - ***Call 410-871-7231 or 410-871-7656 for dates, times, and locations.***
This five week support group is for parents who have lost a baby during pregnancy or shortly after birth.

Healing Hearts Day Camp - ***Registration required* - Call *410-871-7231 or 410-871-7656 for dates, times, and locations.*** Children (ages 7-13) learn ways of coping with grief through a combination of activity and quiet sharing and support.

Camp T.R. - ***Registration required* - Call 410-871-7231or 410-871-7656**
Held at Hashawha Environmental Center, Westminster, MD This weekend grief camp assigns a grief buddy for children (ages 7-15) who have suffered a loss.

- Meets the first weekend in June

Widows Support Group - *No registration required.* This monthly bereavement support group is open to women who have lost a spouse. This group addresses emotional issues surrounding the loss and offers coping strategies.

- First Tuesday of each month from **6:30 PM - 8:00 PM**
- Held at Carroll Hospice, 292 Stoner Ave., Westminster, MD 21157

Widowers Support Group - *No registration required.* This monthly bereavement support group is open to men of all ages who have lost a spouse. This group addresses emotional issues surrounding the loss and offers coping strategies.

- First Tuesday of each month from **6:30 PM - 8:00 PM**
- Held at Carroll Hospice, 292 Stoner Ave., Westminster, MD 21157

Pet Loss Support Group - ***Registration required* - Call 410-871-7231 or 410-871-7656**
This support group is for anyone who has lost a pet. This group addresses the emotional issues surrounding the loss and offers coping strategies.

- Meets quarterly
- Held at Carroll Hospice, 292 Stoner Ave., Westminster, MD 21157

Glade Valley Grief Support Group - ***Registration required.*** *Held at Glade Valley Center, Genesis Health Care, 56 West Frederick Street, Walkersville, MD 21793.* For more information, please call at 410-871-7231 or 410-871-7656. This monthly bereavement support group is open to anyone who has lost a loved one. The group addresses the emotional issues surrounding the loss and offers coping strategies.

CARROLL HOSPICE

292 Stoner Avenue, Westminster, MD 21157
Telephone: 410-871-8000 or 410-876-8044 TTY: 410-871-7186 Fax: 410-871-7242
www.carrollhospice.org

Oct. 2012

Carroll
Hospice

CARROLL HOSPICE BEREAVEMENT SERVICES

◇ BEREAVEMENT SERVICES

- Provide guidance, information, and support for facilitating support groups.
- Facilitate support groups.
- Recommend materials for specific grieving situations.
- Offer workshops on grief topics as requested (students, parents, faculties, churches, community organizations, etc.)
- Provide books, videos, DVDs, etc. through the Bereavement Center Lending Library.
- Support Groups – see reverse side
- One-on-one or small group grief counseling for one or two sessions for the community, including students, parents, school personnel, etc.

› COMMUNITY EVENTS WHICH PROMOTE HEALING

- Coping with the Holidays workshop: in November
- Memorial Tree Lighting: in December

› BEREAVEMENT SKILLS TRAINING: Call for dates and to register.

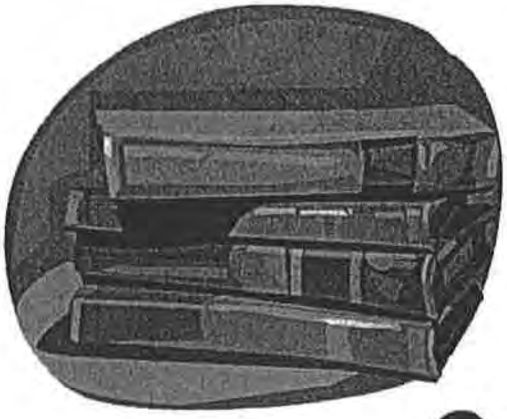
For more information, please contact:
Kathy Bare & Jessica Roschen
Bereavement Counselors
Carroll Hospice, 292 Stoner Avenue., Westminster, MD 21157
410-871-7231 & 410-871-7656
kbare@carrollhospitalcenter.org & jroschen@carrollhospitalcenter.org

292 Stoner Avenue
Westminster, MD 21157

410-871-8000
888-224-2580
Fax 410-871-7242

Carroll Hospice

Bereavement Lending Library



Located at Carroll Hospice
292 Stoner Avenue
Westminster, MD 21157

Open 24 hours

Categories

- Adult Grief
- Care Giving
- Children's Grief
- Hospice
- Death of a Child
- Grief and the Holidays
- Children's Support
- Spanish
- Inspirational and Courage
- Memorials and Funerals
- Men and Grief
- Pet Loss
- Suicide and Sudden Death
- Teen Grief
- Widow and Widowers
- Spirituality

Contacts

Kathy Bare- Bereavement Team Leader
(410) 871-7231

Jessica Roschen- Bereavement Team Leader
(410) 871-7656

Carroll Hospice

Natural Reactions While Grieving

Emotional reactions

- Cry at unexpected times
- Mood swings
- Easily irritated
- Anger, sometimes for irrational reasons
- Guilt
- Fearful
- Depression
- Feeling overwhelmed
- Frustrated by seemingly trivial conversations
- Apathy; lack of interest in people/events that previously caused joy; feeling lazy
- Confused; feel lost, not sure who you are now or what direction life will take
- Wishing to go to sleep and not wake up (however, considering suicide requires seeking help)

Difficulty concentrating

- In a fog
- Wander aimlessly
- Lack of motivation
- Forgetful, lose things, disorganized
- Difficulty making decisions
- Hyperactive
- Mind races or "plays tapes" over and over about the illness/death

Physical reactions

- Headaches
- Tightness or heaviness in chest
- Feeling ill all over
- Empty feeling
- Feeling full of pain
- Feeling tired, even exhausted; want to sleep a lot
- Increased incidents of illness (colds, flu, etc.)
- Lack of appetite or increased appetite
- Increased symptoms of disease or mental health issues
- Difficulty sleeping, bad dreams

Metaphysical reactions

- "See" or "hear" the person who died
- Receive signs (e.g. ladybugs, cardinals, humming birds, butterflies)

Grief facts

- Grief is unique for each person.
- It lasts as long as it lasts- longer than others around you think it should.
- Feelings seem to spiral and/or come and go.
- Feelings need to be released. Crying is good for the body and soul.

"You're not crazy; you're grieving." **Dr. Alan Wolfelt**

292 Stoner Avenue
Westminster, MD 21157

410-871-8000
888-224-2580
Fax 410-871-7242

The Five Myths of Grief

By Alan D. Wolfelt, PhD.

1. Grief and mourning are the same experience.

2. There is a predictable and orderly stage-like progression to experience mourning.

3. It is best to move away from grief and mourning instead of toward it.

4. Tears expressing grief are only a sign of weakness.

5. Following the death of someone significant to you, the goal is to "get over" your grief.

The Five Stages of Grief

by Linda Pastan

The night I lost you
someone pointed me towards
the Five Stages of Grief.
Go that way, they said,
it's easy, like learning to climb
stairs after the amputation.
And so I climbed.
Denial was first.
I sat down at breakfast
carefully setting the table
for two. I passed you the toast-
you sat there. I passed
you the paper-you hid
behind it.
Anger seemed more familiar.
I burned the toast, snatched
the paper and read the
headlines myself.
But they mentioned your
departure,
and so I moved on to
Bargaining. What could I
exchange
for you? The silence
after storms? My typing
fingers?
Before I could decide,
Depression
came puffing up, a poor
relation
its suitcase tied together
with string. In the suitcase
were bandages for the eyes
and bottles of sleep. I slid
all the way down the stairs
feeling nothing.
And all the time Hope
flashed on and off
in defective neon.
Hope was a signpost pointing
straight in the air.
Hope was my uncle's middle
name,
he died of it.
After a year I am still climbing,
though my feet slip
on your stone face.
The treeline
has long since disappeared;
green is a color
I have forgotten.
But now I see what I am
climbing
towards: ***Acceptance***
written in capital letters,
a special headline:
Acceptance
its name is in lights.
I struggle on,
waving and shouting.
Below, my whole life spreads its
surf,
all the landscapes I've ever
known
or dreamed of. Below
a fish jumps: the pulse
in your neck.
Acceptance. I finally
reach it.
But something is wrong.
Grief is a circular staircase.
I have lost you.

Reconciliation Needs of the Mourner

by Dr. Alan Wolfelt

1. To experience and express outside oneself the reality of the death.
2. To move toward the pain of the loss while being nurtured physically, emotionally, and spiritually.
3. To convert the relationship with the person who has died from one of interactive presence to one of appropriate memory.
4. To develop a new self-identity based on a life without the person who has died.
5. To relate the experience of death to a context of meaning.
6. To have an understanding support system available to you in the months and years ahead.

FACTORS THAT NATURALLY INFLUENCE COMPLICATED MOURNING

1. The death itself
2. Survivor's psychological traits/personality
3. Survivor's relationship with the person who has died
4. Survivor's capacity to mourn
5. Survivor's family system

Sudden, Unexpected, Violent Death

Trauma

Nature of the death

Heightened unreality

Helplessness/ Rage

Agitation/Restlessness

Increased Need to Understand

Vulnerability/Fear

"If onlys"

Stigmatism

Common Patterns of Avoidance

by Alan D. Wolfelt, PhD

The Postponer - if you delay the expression of grief, it will hopefully go away; the grief builds up inside pushing toward the point of explosion; can be an automatic unconscious response

The Displacer - takes the expression of grief away from the loss and displaces the feelings in other directions, may complain of difficulty at work or relationship problems; easily agitated and upset at minor events; mostly unconscious response

The Replacer - takes the emotions that were invested in the relationship and reinvests the emotions prematurely in another relationship; others will assume that person did not love the one who died that much, actually the person loved very much and the need to overcome the pain results in an avoidance pattern of replacement; little, if any, conscious awareness of replacement

The Minimizer - minimizes feelings of grief to rationalize that he is not affected by the loss; often conforms to society's message to "get over it"; believes that grief is something to be quickly **thought** through but not **felt** through

The Somaticizer - converts feeling of grief into physical symptoms; minor complaints to malignant chronic pattern (vague complaints with no organic findings); by taking on the "sick role" people legitimize their need to be nurtured and comforted; this is different than the real physical symptoms that often occur with grief; there is a definite physical risk for the griever, a general medical exam is in an excellent standard of care

The Worker - begins to "over invest" in work to the point where no time is available to think or feel about the loss; often following the advice of well wishers who encourage him to "keep busy"

The Shopper - spends money in an effort to avoid the work of mourning; "retail therapy"; provides short-term relief before another "fix" is needed

The Eater - has continual cravings for food; experienced as a compulsion; may be trying to fill a void from the emptiness inside his or her body; they are "consuming their grief"

The Chemical Abuser - uses alcohol and/or other drugs to avoid the work of mourning; behavior often reinforced with comments like, "Here take this, it will make you feel better."; among the most dangerous avoidance patterns; can become a destructive pattern of behavior that blocks the work of mourning for years in the future

The Traveler - stays on the move to avoid the work of mourning; often reinforced with comments like, " What you need to do is get away, take a trip," the message is that you can leave your grief behind; paradoxically may begin to miss what was left behind such as, support systems and comforting routines

The Crusader - converts his or her grief into over-dedication or premature involvement with a cause; behavior often reinforced with comments like, "The thing that will help you help yourself, is getting involved in helping others."; distracting the mourner from the work he or she needs to do

Five "Be"s for the Grief Helper

1. **Be** present

Your physical presence is more important than words. Don't avoid a grieving person because you don't know what to say. Continue to visit after the shock and busy-ness have subsided and loneliness has taken their place.

2. **Be** aware

Look for ways to be of specific help and *act* rather than say, "If there is anything I can do, don't hesitate to call." Shop for groceries; take care of the laundry; offer to babysit.

3. **Be** accepting

Permit the bereaved to grieve and give expression to emotions through natural and often necessary feelings like anger, denial, shock, guilt, depression, loneliness, crying.

4. **Be** a listener

Give the grieving person opportunity to talk about the loss as much and as often as needed. Permit the bereaved to be in control. Avoid phrases like, "You shouldn't say that" or "You shouldn't feel that way."

5. **Be** patient

Each person's way of grieving differs in length and intensity. The emotions of grief may be experienced more than once with varying degrees of intensity. It is not uncommon for the process of overcoming grief to take several years.

Tear Soup, a recipe for healing after loss.

By Pat Schwiebert & Chuck DeKlyen Illustrated by Taylor Bills

Helpful ingredients to consider

* a pot full of tears
* one heart willing to be broken open
* a dash of bitters
* a bunch of good friends
* many handfuls of comfort food
* a lot of patience
* buckets of water to replace the tears
* plenty of exercise
* a variety of helpful reading material
* enough self care
* season with memories
* optional; one good therapist and/or support group

Directions:

Choose the size pot that fits your loss. It's ok to increase the pot size if you miscalculated. Combine ingredients. Set temperature for a moderate heat. Cooking times will vary depending on the ingredients needed. Strong flavors mellow over time. Stir often. Cook no longer than you need to.

Suggestions

* be creative
* trust your instincts
* cry when you want to, laugh when you can
* freeze some to use as a starter for next time
* write your own soup making in a journal so you won't forget

Serves One

FROM ***TEAR SOUP,*** *a recipe for healing after loss.* **Available Through Grief Watch**

By Pat Schwiebert & Chuck DeKlyen Illustrated by Taylor Bills

Tear Soup Cooking Tips

Reprinted from
TearSoup, a recipe for healing after loss

Grandy's Cooking Tips

- Grief is the process you go through as you adjust to the loss of anything or anyone important in your life.
- The loss of a job, a move, divorce, death of someone you love, or a change in health status are just a few of the situations that can cause grief.
- Grief is both physically and emotionally exhausting. It is also irrational and unpredictable and can shake your very foundation.
- The amount of "work" your grief requires will depend on your life experiences, the type of loss, and whatever else you have on your plate at that time.
- A sudden, unexpected loss is usually more traumatic, more disruptive and requires more time to adjust to.
- If your loss occurred through violence, expect that all the normal grief reactions will be exaggerated.
- You may lose trust in your own ability to make decisions and/or to trust others.
- Assumptions about fairness, life order, and religious beliefs are often challenged.
- Smells can bring back memories of a loss and a fresh wave of grief.
- Seasons, with their colors and climate, can also take you back to that moment in time when your world stood still.
- You may sense you have no control in your life.
- Being at work may provide a relief from your grief, but as soon as you get in the car and start driving home you may find your grief come flooding back.
- You may find that you are incapable of functioning in the work environment for a short while.
- Because grief is distracting it also means you are more accident-prone.
- The object of grieving is not to get over the loss or recover from the loss but to get through the loss.
- Over the years you will look back and discover that this grief keeps teaching you new things about life. Your understanding of life will just keep going deeper.

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Tear Soup Cooking Tips

Reprinted from
TearSoup, a recipe for healing after loss

If you are the cook

- This is your grief—no one else's. Your friends can't feel your loss in the same way. It will not affect their life the way it affects yours. And you may resent them for that.
- At first you may think dying would be preferable to having to go through this pain. Just try to stay alive. Sudden mood swings are normal. You may suddenly be unreasonable and short.
- Try your best to educate your friends about what you need and how they can help. Be as honest as you can be about how you are feeling.
- Don't give up on your friends if they let you down. But if they continue to be insensitive to your grief you may need to distance yourself for a while until you get stronger.
- At first you will probably want to talk to as many people as possible, but after a month or so, find one or two people whom you can count on for the long haul to just be there and listen when you need to talk.
- Write your thoughts in a journal. It will help you to process and also to remember the new insights you are learning.
- Consider attending a support group. Go at least three times before deciding if it is helpful to you.
- Be open to counseling.
- Exercise, sleep, drink plenty of fluids, and eat a well balanced diet.
- Pamper yourself. Take bubble baths. Get a massage.
- Try not to compare your grief with another's. You don't earn points for having a more painful experience than someone else has. And you won't feel less grief if someone else's loss is worse.
- You deserve to feel happy again. Being happy doesn't mean you forget. Learn to be grateful for the good days.
- Don't be too hard on yourself.
- Long after everyone else has forgotten your loss, you will continue to remember. Learn to be content with your private memories.

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If your friend is the one who is making Tear Soup

- Be there for your friend, even when you don't understand
- Be a source of comfort by listening, laughing, and crying
- Stick close to your friend and defend their right to grieve
- Allow your friend to make mistakes... or at least to grieve differently from the way you would grieve.
- Send flowers. Send money if you know this would help.
- Send cards. The message doesn't need to be long. Just let them know you haven't forgotten them. Send one every few weeks for a while.
- Call your friend. Don't worry about being a bother. Let your friend tell you if they don't want to talk about their loss right now.
- Answering machines and e-mail are great ways to keep in touch allowing the bereaved person to respond only when they feel up to it.
- Try to anticipate what your friend may need. Bereaved persons sometimes don't know what to ask for.
- Avoid offering easy answers and platitudes. This only invalidates grief. Be patient. Don't try to rush your friend through their grief.
- Give your friend permission to grieve in front of you. Don't change the subject or tell them not to cry or act uncomfortable when they do cry.
- Ask them questions. But don't tell them how they should feel.
- Invite your friend to attend events together, as you normally would. Let them decide if they don't want to attend.
- Don't assume because your friend is having a good day that it means they are over heir loss.
- Be mindful of holidays, birthdays and anniversaries

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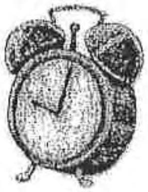

Soup Making and Time

- Grief work takes time. Much longer than anyone wants it to.
- If a child or spouse dies it may be a year before the bereaved begins to gain a sense of stability, because the loss is highlighted by each season, holiday, anniversary or special day. The second year is not so great either.
- You may be okay one minute but the next minute you may hit bottom.
- Nighttime can be particularly difficult. Some people have trouble getting to sleep while others have trouble staying asleep. And then there are those who don't want to wake up.
- Most people can tolerate another's loss for about a month before wanting the bereaved person to get back to normal.

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Tear Soup Cooking Tips

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If you are a male chef

- The world may not see you the bereaved person that you are. Because of your gender, in our society you may be seen only as the support person–a role you probably play very well.
- If you have been taught from an early age that "big boys don't cry," you may feel ashamed of your own tears. Other people may also be uncomfortable with your tears.
- Don't hold your grief in Find a safe place or someone who is not afraid of your grief.
- People may tell you how strong you are when you hold in your grief. Don't confuse grieving with weakness and not grieving with strength. In fact, holding grief in is very hard on your body and can weaken your health.
- Gender does not *determine* your grieving style, but it may *affect* the way you grieve.
- Assume that your initial response to grief is the right response for you at that time Try not to behave as others think you should–but as you need to.

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Tear Soup Cooking Tips

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If there are two of you cooking

- Grief is unique to the individual. You may both experience the same loss, but you won't grieve in the same way. In other words, you are in it together, but you are in it alone.

- At first you may feel closer to each other than ever before. But that may change the farther you get away from your shared loss.

- Try not to judge each other.

- Talk to each other when you can.
- Don't let your partner be your only source of comfort.

- Write each other notes.

- It is normal to want others to grieve the same way you grieve and to communicate the same way you communicate. But life is just not that easy.

- Sexual desire may be affected. You both need intimacy, but not necessarily sex. Talk about it.

- Remember the past, hope for the future, but live in the present.

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Suggestions For Friends And Relatives Of The Grieving Survivor
"Is There Anything I Can Do To Help?"

Yes, there is much you can do to help. Simple things. This guide suggests the kinds of attitudes, words, and acts, which are truly helpful.

The importance of such help can hardly be overstated. Bereavement can be a **life-threatening condition**, and your support may make a vital difference in the mourner's eventual recovery.

Perhaps you do not feel qualified to help. You may feel uncomfortable and awkward. Such feelings are normal - don't let them keep you away. If you **really care** for your sorrowing friend or relative, if you can enter a little into his or her grief, you are qualified to help. In fact, the **simple communication of the feeling or caring** is probably the most important and helpful thing anyone can do. The following suggestions will guide you in communicating that care.

1. Get in touch. Telephone. Speak either to the mourner or to someone close and ask when you can visit and how you might help. Even if much time has passed, it's never too late to express your concern.

2. Say little on an early visit. In the initial period (before burial), your brief embrace, your press of the hand, your few words of affection and feeling may be all that is needed.

3. Avoid clichés and easy answers. "He is out of pain" and "aren't you lucky that..." are not likely to help. A simple "I'm sorry" is better.

4. Be yourself. Show your natural concern and sorrow in your own way and in your own words.

5. Keep in touch. Be available. Be there. If you are a close friend or relative, your presence might be needed from the beginning. Later, when close family may be less available, anyone's visit and phone call can be very helpful.

6. Attend to practical matters. Find out if you are needed to answer the phone, usher in callers, prepare meals, clean the house, care for the children, etc. This kind of help lifts burdens and creates a bond. It might be needed well beyond the initial period, especially for the widowed.

7. Encourage others to visit or help. Usually one visit will overcome a friend's discomfort and allow him or her to contribute further support. You might even be able to schedule some visitors, so that everyone does not come at once in the beginning and fails to come at all later on.

8. Accept silence. If the mourner doesn't feel like talking, don't force the conversation. Silence is better than aimless chatter. The mourner should be allowed to lead.

9. Be a good listener. When suffering spills over into words, you can do the one thing that the bereaved needs above all else at that time - **you can listen.** Is she emotional? Accept that. Does he cry? Accept that too. Is she angry at God? God will manage without your defending Him. Accept whatever feelings are expressed. Do not rebuke. Do not change the subject. Be as understanding as you can be.

10. Do not attempt to tell the bereaved how he or she feels. You can ask (without probing), but you cannot know, except as you are told. Everyone, bereaved or not, resents an attempt to describe his feelings. To say for example, "You must feel relieved that he is out of pain," is presumptuous. Even to say, "I know just how you feel," is questionable. Learn from the mourner; do not instruct.

11. Do not probe for details about the death. If the survivor offers information, listen with understanding.

12. Comfort children in the family. Do not assume that a seemingly calm child is not sorrowing. If you can, be a friend to whom feelings can be confided and with whom tears can be shed. In most cases, incidentally, children should be left in the home and not shielded from the grieving of others.

13. Avoid talking to others about trivia in the presence of the recently bereaved. A prolonged discussion of sports, weather, or the stock market, for example, is resented, even if done to purposely distract the mourner.

14. Allow the "working through" of grief. Do not whisk away clothing or hide pictures. Do not criticize seemingly morbid behavior. Young people my repeatedly visit the site of a fatal accident. A widow may sleep with her husband's pajamas as a pillow. A young child may wear his dead sibling's clothing.

15. Write a letter. A sympathy card is a poor substitute for your own expression. If you take time to write of your love for and memories of the one who died, your letter might be read many times and cherished, possibly into the next generation.

16. Encourage the postponement of major decisions. Whatever can wait should wait until after the period of intense grief.

17. In time, gently draw the mourner into quiet outside activity. He may lack the initiative to go out on his own.

18. When the mourner returns to social activity, treat him or her as a normal person. Avoid pity - it destroys self-respect. Simple understanding is enough. Acknowledge the loss, the change in the mourner's life, but don't dwell on it.

19. Be aware of needed progress through grief. If the mourner seems unable to resolve anger or guilt, for example, you might suggest a consultation with a clergyman or other trained counselor.

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The House is Empty Now

The house is empty now, and so am I.
The silence is all around me
and penetrates my every step.
If I listen to music, it pierces my soul
and brings up tears on its way out.

I see her picture on several walls,
giving a momentary glow
to days gone by, filling those rooms
with love's reflections, as I pass through.

I go out and return, but the routine and the voices
beyond this place cannot come back with me.
I am stripped and searched at the door,
humbled as I lean upon the entrance way.
I may only take the emptiness in.

That doesn't seem necessary,
since it abides here anyway.
The house is empty now,
and so am I.

~By Reverend William E. Gramley

Carroll
Hospice

A Time To Mourn

I am lost in grief, numb with shock,
Filled with disbelief and at times, rage -
Besieged by an army of rebellious emotions,
My instinct is to retreat.

I want to hide under a blanket and sleep,
Awakening only to your smiling face.
But the nightmare is real -
And you are not coming back.

I am a worry to my family
And a stranger to our friends,
Adrift in a sea of despair
And marooned in an unwelcome reality.

Please don't rush my grief
Or tell me to move on with my life.
I need time.
My loss must be processed, my pain
must be healed.

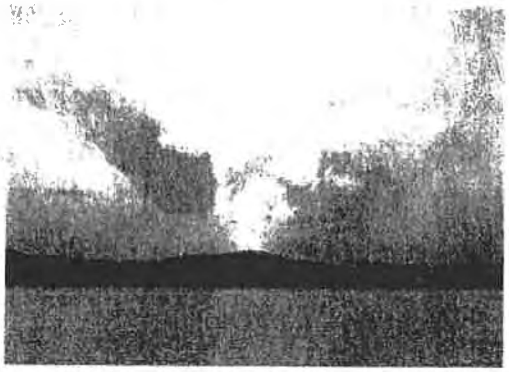
Please be gentle and kind.
Offer a hot meal - not advice!
Share a cup of tea.
Understand my silence may be from fatigue and
emptiness within.
Please don't shy away when I vent anger and frustration.
I may even seem bitter and envious of those around me.

Have patience as I reminisce and gaze fondly at old
photographs.
Speak my beloved's name and smile as we reflect
shared memories.
I am not afraid of tears -
Only the loneliness each day brings.

Grieving takes time. Grieving requires support.
Embrace me with love. Companion me with hope.
My faith gets me out of bed -
Your support keeps me going.

Thank you for being my friend.

Jill Englar© 2002



Please Be Gentle

An After Loss Creed

Please be gentle with me for I am grieving
The sea I swim in is a lonely one
And the shore seems miles away.
Waves of despair numb my soul
As I struggle through each day.

My heart is heavy with sorrow.
I want to shout and scream
And repeatedly ask "Why".
At times, my grief overwhelms me
And I weep bitterly,
So great is my loss.

Please don't turn away
Or tell me to move on with my
life.
I must embrace my pain
Before I can begin to heal.

Companion me through tears
And sit with me in loving silence
Honor when I am in my journey
Not where you think I should be.

Listen patiently to my story.
I may need to tell it over and over again.
It's how I begin to grasp the enormity of my loss.

Nurture me through weeks and months ahead.
Forgive me when I seem distant and inconsolable.
A small flame still burns within my heart
And shared memories may trigger both laughter and tears.

I need your support and understanding.
There is no right or wrong way to grieve.
I must find my own path.
Please, will you walk beside me?

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CARROLL HOSPICE

BEREAVEMENT SERVICES

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www.carrollhospice.org

Mourning Exercises

Make a Memory Book: Using a scrapbook or photo album put together a collection of favorite mementos. Suggestions: Photos, ticket stubs, party favors, letters, and notes

How about a Memory Box?: Similar to the book, but use a cardboard box or one of those nice plastic containers to store objects with special meaning. Did you know that you can store a piece of clothing in a zip-lock bag, and it will hold the smell for a long time? Many people report having nice memory embraces by taking out a piece of clothing that has the scent of their loved one.

Journal: Buy a blank book or use a notebook to chronicle your life during your grief journey. Record thoughts, poems, feelings, ideas. Go back often and review previous entries - look at the changes taking place in you! Some people also use their journal to draw or doodle as a way to show how they are feeling

Life History and Review: Put together a history of you and your loved one. Start with the day you met, or day of birth of the deceased. Sometimes individuals find it helpful to put together a chronicle of the time of illness.

Express Yourself: Draw out your feelings - Draw, color, paint, or sculpt. Your finished project can be a representation of your loved one or an avenue for your intense feelings.

Music: Listen to music that connects you to your loved one. Play different kinds of music to facilitate your range of emotions. Write a song, or put your own words to someone else's tune.

Memory Table: Have a special place to put a favorite photograph and some precious mementos. Decorate with lace doilies and a candle. Use this spot as a place where you can stop to pause and reflect.

Cemetery: Visit the gravesite at a meaningful time of the day, for example, sunset. Talk, read something, or cry to your loved one. Leave special objects on the grave: flowers, balloons, toys, notes. Sit quietly to meditate and reflect. Say good-bye when you leave.

Memorialize: Plan a memorial or remembrance service. Choose a time that's meaningful and healing to you: 1 month, 6 months, 1 year. Some choose the birthday of the deceased or a wedding anniversary. Times of remembrance can be formal or informal; some people have a Mass, others have a party. Use a church, your home, or the outdoors.

Memory Basket: On small pieces of paper, write down memories of your loved one. Drop them into a basket or container. Take them all out and read them from time to time, continuing to add to the basket. Use the basket as long as you need to, some store the contents away with plans to give them to another relative or friend. Some individuals turn these pieces of paper into a book about their loved one.

Support: You may find it healing to join or lead a support group. Support groups allow you to receive validation from others about your grief experiences. Many find it helpful to be able to tell their story.

These are just a few suggestions to help you begin your healing. Choose mourning practices that feel true to you. Remember, everyone's grief is unique.

HEALING

one thing I forgot:

after the
pain of parting
comes the
happiness of healing;

rediscovering
life,
friends,
self.

Joy.

~Colgrove, Bloomfield, McWilliams

De-Stressing the Holidays

By Susan Marinac, LISW
smarinac@buschfuneral.com

For many people the holiday season can mean stress and frustration instead of peace and joy. Family issues, time constraints, finances and a sense that everything must be "perfect" can lead to feelings of depression and a sense of feeling overwhelmed. In today's society we are so inundated with visual images of the perfect family, the perfect home, the perfect holiday gathering, that it can be difficult to set realistic expectations for ourselves. The holiday "season" begins earlier and earlier every year. Stores are creating their holiday displays well before Halloween. The season grows longer and longer every year and our patience grows shorter.

The good news is we can simplify the holidays, reduce our stress and create more quality time with family and friends. First, we need to set realistic expectations and not compare ourselves to others. Whatever way you choose to celebrate is right for you. Sometimes we think that we must have things a certain way because that is how we've "always done it." Really, it is okay to change and to eliminate some things, especially if they are causing stress. For example, there's no need to spend so much money during the holidays. The things that we desire the most: love, friendship, companionship, cannot be bought. Try a gift "lottery" or a white-elephant gift exchange instead of buying gifts for every member of your family this year. Or decide as a family that you are all going to donate to a charity in lieu of giving gifts. Then have a family meeting where you talk about the charity and your reasons for giving.

It is unfortunate but true that the times we are stressed tend to be the times that we don't do what we know will help us. Even if we know what we should be doing, it doesn't help unless we actually do it. Following are some strategies that can help us cope.

1. **Accept your feelings.** Feelings are neither right nor wrong. They are just feelings. We need to laugh and to cry. It is normal to express your feelings and you do not have to be in a good mood just because it is the holiday season.

2. **Reach out to others.** If you are feeling down or lonely, call a friend and go out for a cup of coffee. You may want to get involved with your church, sign up for a class or volunteer. Even if you do not have many family members, you do not have to go through the holidays alone.

3. **Get organized.** Develop your holiday plan ahead of time when you are not so busy. Set aside time for all of your activities and schedule it on your calendar. Schedule in all of the preparation time you need as well. This will help to avoid last minute scrambles.

4. **Know thyself.** Learn to say no if you need to. We all have limits. People really do understand when you cannot commit to everything. Don't take on more than you can handle or you may become angry and resentful.

5. **Take time to breathe.** Spending even ten minutes alone just relaxing and focusing on your breathing can be a huge stress reducer. You can also listen to soothing music to enhance relaxation.

6. **Move it.** Schedule time for exercise. Walking is great exercise and the perfect activity to start an exercise program. Gentle stretching before going to sleep at night will promote relaxation and help you to get a better night's sleep. You will wake up feeling refreshed and more focused.

7. **Delegate.** You do not have to do everything yourself. Enlist other family members to take on tasks.

8. **Zzzzzz.** Healthy sleep habits are essential. Try to get eight hours of sleep per night and do not consume any caffeine after three p.m.

9. **Healthy eating.** We are so tempted throughout this season to consume more than we are used to. Watch the sweets. Try drinking a large glass of water before the next holiday party so you will feel more full and not want to pick.

10. **Seek professional help if needed.** If you find you have a permeating sadness that you cannot shake or if you are plagued by feelings of helplessness, anxiety or despair, you may need the advice of a professional. Talk to your doctor and he or she can assist you.

Above all, go easy on yourself. It's okay to make mistakes. Try and incorporate one positive idea into each day and then reflect on the day before you go to bed to see how you could improve or pat yourself on the back for a job well done. If you take the time to remember what is most important and seek support if you need it, you can truly have a happy holiday.

Carroll Hospice

Grief and Bereavement Websites

dougy.org (The National Center for Grieving Children and Families)
support for grieving children, teens, young adults and their families; offers an on-line support community

centerforloss.com
support for mourners, and professional and lay caregivers

centering.org
providing education and resources for the bereaved

hospicenet.org
hospice, grief, and bereavement information

griefnet.org
dealing with grief, death, and major loss; e-mail support groups

myadultsiblinggrief.com
for those who have suffered the loss of an adult sibling

siblingsurvivors.com
for sibling survivors of suicide; on-line guest book

counselingstlouis.net
a resource for anyone who has lost a sibling; on-line message board

allkidsgrieve.org/category/grieving
parenting resource for helping children cope

compassionatefriends.org
support after a child dies; on-line support/live chats

agoodgrief.com
child loss; offers on-line forums

silentgrief.com
for anyone who has been touched by child loss; chat boards

wintergreenpress.com
support resources for perinatal loss and infant death

1stbreath.org
"Honoring those who never took a breath ..."

missfoundation.org (Mothers In Sympathy and Support)
support for families after the death of a child from birth to adult from any cause; on-line support forums

firstcandle.org
provides grief support to all those affected by the death of a baby; grief counselors available 24/7

mend.org (Mommies Enduring Neonatal Death)
loss of a baby through miscarriage, stillbirth, or early infant death

bereavedparentsusa.org
helping grieving parents and families rebuild their lives following the death of a child

bereavementmag.com
bereavement publications

griefsong.com
grief songs for grief support, bereavement, hospice, funerals, and hope by Paul Alexander

griefwatch.com
provides bereavement resources and memorial products

griefshare.org
grief recovery support groups; seminars and support groups

groww.org
grief recovery on-line for all bereaved

forums.grieving.com
help for coping with loss; on-line grief support

webhealing.com
grief resources; discussion boards

compassionbooks.com
books, videos, and audios for losses of all kinds

Listing of websites does not imply endorsement by Carroll Hospice, but is provided as a source of information for bereaved families.

For more information, please contact:
Carroll Hospice Bereavement Counselors
Kathy Bare, kbare@carrollhospice.org, 410-871-7231
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Sept. 2012

Children

CHILDREN AND GRIEF

OVERVIEW

Because a child may be part of the family unit, their needs require awareness and sensitivity.

LEARNING OBJECTIVES

By the end of this session, participants will be able to:

1. Describe children's developmental stages and their range of understanding of death at each age.
2. Recognize typical reactions of children involved in the approaching death of a family member.
3. Communicate with the grieving child, using techniques shown effective by research.
4. Select books that would help children deal with grieving and death.

the Eucalyptus Tree

A Program of Cedar Valley Hospice

Family Packet

Cedar Valley Hospice

Making Each Moment Matter

P.O. Box 2880 Waterloo, Iowa 50704-2880 319-272-2002

Welcome to the Eucalyptus Tree

You have received this packet because you have an interest in how to support a grieving child. The Eucalyptus Tree is a unique and comprehensive program designed for you and the young people you care about.

Children grieve differently than adults. Their understanding of the world and their ability to comprehend the meaning and permanence of death changes as they grow and mature. Informed adults make terrific listeners and are able to provide clear and accurate information for kids. We offer young people healthy ways to express themselves, opportunities to connect with others their age who have experienced similar losses, and information and support for both the youth and the adults who care for them.

Our program is based on three basic assumptions about children and grief. First, **death is a natural part of living.** We talk about death openly and encourage children to share their stories, feelings, and questions.

Second, **grief is a normal part of loss.** We help children understand that their feelings and reactions are normal and necessary.

Finally, **honesty is important.** We work with families to find the best ways for them to discuss a difficult subject with honesty and sensitivity.

We invite you to review the enclosed materials as a preview to your journey together. You will find a description of The Eucalyptus Tree Program services within. Please contact us if we can answer questions or provide additional support to you and your family.

The Eucalyptus Tree Staff

If you have questions,

please call us at (319) 272-2002
or email us at sbaranowski@cvhospice.org

the Eucalyptus Tree

Cedar Valley Hospice

A Child's Understanding

about death

A child's ability to understand the concept of death and what it means to him/her varies with the child's age. Adults need to be aware of the understanding level of the child and adjust any explanation to that level. The most important thing to remember is to be as accurate, honest, and open as possible. Do not give elaborate explanations. Giving more than he/she can understand only confuses the child. Encourage questions and assure that any emotions being felt are the same feelings other children in similar situations have felt.

The following list can serve as a loose guide to a child's development stages, reactions to death and possible behavioral indicators of grief.

Under 2 Years of Age

- Can sense that something is different, that there is a change in the emotional atmosphere
- Does not understand yet what death is
- Probably won't remember the person who died
- Needs a lot of nonverbal communication (i.e hugs, rocking, continued routine)
- Indicators: fussy, clings to adults, regression

3 - 5 Years of Age

- Sees death as temporary, believes that the person will return or can be visited
- Has difficulty handling concepts such as heaven, the soul or spirit
- Feels sadness, but often for only a short time and then escapes into play, giving adults the impression the child isn't really grieving
- Substitutes attachment to another person in exchange for attachment to person who died
- Needs a daily routine, structure, affection and reassurance
- Indicators: regression, nightmares, aggression, non-compliance

5 - 9 Years of Age

- Begins to understand that death is final and permanent
- Begins to have a fear of death and of others dying
- May feel guilt (magical thinking) and blame self for the death
- Indicators: compulsive caregiving, aggression, possessiveness, regression, headaches, stomachaches, phobias

A Child's Understanding About Death - 2

10 - 12 Years of Age

- Recognizes that death is inevitable and irreversible
- May view death as a punishment
- Retains some elements of magical thinking
- Often very curious and interested in the "gory" details
- May come up with own theories or explanations of the reasons for the death
- May have many practical questions about the body, the funeral, etc.
- Indicators: aggression, possessiveness, headaches, stomachaches, phobias, defiance

13 - 18 Years of Age

- Nearing adult levels of concepts
- May worry or think about own death
- Often avoids discussions of death
- Fears "looking different"
- Often angry at the deceased
- Indicators: aggression, possessiveness, headaches, stomachaches, phobias, increased sexual activity, increased drug use, increased risk-taking, defiance, suicidal ideation

Note:

Emotionally and cognitively, all of the above groups may exhibit irritability, anxiety, lowered self-esteem, apathy, depression, feelings of rejection, distractibility, short attention spans, and a decline in school work or usual ability to attend to a task or play.

A Child's Grief

an explanation of terms and concerns

Forgotten Mourners

Children are often not allowed to engage in the formal grief process. When a life threatening illness occurs, adults consumed with their own need for support may not be able to support children. When the family begins to make decisions regarding the person who is ill, the children in the family are seldom included. Children who are prepared can make the decision whether to visit the loved one. In the event the person dies, children should be allowed to make the decision whether to attend the funeral, visit the cemetery, or create an individual way to say goodbye to the dying or deceased person. This is crucial for the grieving child and adults must remember to include them in these decisions.

Some of the most beautiful funeral services have portions written and performed by children. These families know the importance of allowing a child to mourn openly and publicly in a formal ceremony. A school principal speaks eloquently of being seven years old and not being allowed to attend the funeral of his mother. Now in his forties, he feels that he never had the opportunity to say good-bye. He now wonders what was so secret that he could not be a part of it.

Magical Thinking

Children cannot use the same logic as adults. Many children can suffer intense guilt because they believe that a momentary thought, wish, or action actually caused someone's illness. For instance, a child who accidentally breaks grandma's vase may hear her say, "Child, you'll be the death of me yet." If, two months later, the grandmother dies of a heart attack, the grandchild may think, "If I had been good and not broken that vase, Grandma would be alive today." A child may be jealous of a baby brother and wish that the baby had never been born. Later, if the baby gets very sick and is in the hospital, the child may believe it was that wish that made the baby brother ill. Children may feel so guilty that they cannot "confess" their guilt to an adult. Children need to be reassured that there was nothing they could have done to prevent an illness or death.

For other children, magical thinking involves believing some external force came and caused a life threatening illness. They may believe that a mother's illness wasn't due to leukemia, but because something mean and evil like a ghost, demon, witch, or super villain came and snatched the mother's health away. Such children are often terrified, especially around Halloween. They must get accurate information about the illness and be reassured that such creatures do not exist.

A Child's Grief - 2

On and Off Grief

Children have the unique ability to grieve intermittently. Unlike adults, who often grieve intensely without relief or interruption, children are able to take "mini-vacations" when the emotions become too intense and overwhelming. It puzzles adults to observe children crying uncontrollably at a hospital or at home in the morning, but running and playing after lunch. A parent may watch a child eat a hearty dinner, but be tearful and sleepless that night. These on-again, off-again grief reactions are confusing to adults. Some become suspicious that the child is possibly trying to manipulate the adult to get sympathy or special treatment. Unfortunately, many interpret such behaviors as an example of just how quickly children recover from their grief. Grief researchers feel that neither is usually true. Children merely grieve off and on as a means of self-protection. In reality, their grief is no shorter than an adult's grief and in some cases is actually longer. Adults need to be wary of assuming a child is no longer grieving when, in actuality, they may just be on a short vacation from the situation and the accompanying feelings.

Literal and Concrete Thinking

Children think literally and concretely. They do not have a wide vocabulary and cannot sense subtle differences between terms. Therefore, softening the discussion by using euphemisms often backfire. Telling a small child that her hospitalized grandfather is on a long trip invites the child to ask, "When is he coming back?" or "Why didn't he take me with him?" Explaining that a person who is in a coma or is unresponsive is merely asleep can be extremely frightening for a child. Children who believe that there is no difference between death and sleep can become afraid to take naps or go to bed. Use simple words and sentences to explain an illness to a child. They need honest information, but they don't need a lengthy explanation.

Regrieving the Loss

For children, each new developmental stage may bring an upsurge of grief about a past loss. This occurs as they become more fully aware of the illness' impact on their life. A child whose parent is bedridden when she is five may regrieve the loss at the age of seven when she becomes a campfire girl. Daddy is not able to do certain activities with her and she realizes for the first time the seriousness of the illness. She may regrieve again when she receives a sports award, goes to prom, graduates from high school, gets married, or has a baby. At each developmental milestone, the acuteness of the loss can come out in some new and unexpected way. Children are unlike adults who often have upsurges of grief on certain dates such as an anniversary or birthday. A child's grief is not so tightly connected to a date. It is more likely tied to a personally important life event that they would have liked to have shared with the ill or deceased person.

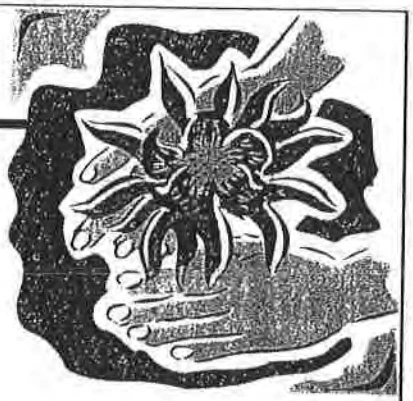
Experience and Process Through Play

The language of children is play. Often they do not have the verbal skills or vocabulary to express feelings and ideas, but they do have the ability to play out these feelings and ideas. Children who have experienced an illness may be observed reenacting a hospital visit with their dolls, playing doctor or surgery, or acting out a family squabble with their action figures. To an adult onlooker, the behavior may seem morbid, but children are merely taking the information they have and processing it through their play activities. In this way, they can resolve in their minds what has happened and how. Grown-ups can be reassured that such behavior is very normal and adults can take this opportunity to join in their play and "narrate" for children what may have actually happened.

School

Children often exhibit some difficulties with school when coping with a family illness. A grieving child usually has difficulty concentrating, sitting still, or doing demanding assignments. Some children may act out due to anger or guilt feelings regarding the illness. There may be changes in the child's relationships with other children. A child may withdraw or become the class clown. Some changes may be so subtle that school personnel may not pick up on them. A child might lose interest in eating lunch, participate unenthusiastically in gym class, or begin to draw dark and depressing pictures. Immediately after a chronic or terminal illness has been diagnosed, if school officials have been notified, staff is often alert to these changes, but as the months wear on, many adults assume that a child should have resolved the grief. After a period of time, if the difficulties persist, children can be labeled as having "Attention Deficit Disorder" or "other behavioral disorders" because someone has determined that it cannot possibly be grief reactions after this length of time. Parents should remind school personnel if there has been a significant illness or death in the family for up to two years after the death. School staff should especially be made aware of any death situation when there has been a change in the school year or teacher, when a child has moved to a new school, or when there has been a subsequent illness or death in the family circle. This allows school staff to be aware of changes in the child's normal behavior patterns and deal with the situation quickly and effectively.

Should Children attend funerals?



This is probably one of the most common questions regarding children and grief. Most grief experts agree that the following points need to be made when considering this issue.

- Try to include children in the family grieving process. Think about allowing them some level of involvement in the funeral arrangements, viewing or service for their deceased loved one. Begin by describing to them what will happen at the visitation or funeral and allow them to decide for themselves whether or not to attend.
- If there is to be a viewing, describe this to the child in detail ahead of time. Talk about what the casket and body will look like. Explain to the child that even though it may appear that their loved one is sleeping, this is not the case. Use the language that reinforces this (dead, death, died). Try to reinforce to the child that their loved one can no longer feel anything.
- It is a good idea to let the child know that there will be many people present. They should be told that everyone displays their emotions differently. Some people may cry and others may not show their feelings at all. Tell them that even the adults that usually are very composed may appear more emotional than usual. The child should know that is okay for them to cry, as well as to laugh and enjoy memories, at the funeral or visitation.
- Sometimes adults are worried that the child may disturb others with their behavior at the service. Define acceptable behavior for the child and have a back-up plan in place just in case unsuitable noise or activity occurs. A trusted family friend is usually happy to "keep an eye out" for the child and will agree to leave with them if the need arises. This would be especially helpful for parents who feel the need to focus on their own grief reactions.

Children's grief expert, Dr. Alan Wolfelt says, "The funeral, a ritual that has been with us since the beginning of time, is here to help us embrace the life that was lived and support each other as we go forward. As caring adults, we will service our children to introduce them to the value of coming together when someone we love dies."

(Compiled by Hamilton's Funeral Home, Des Moines)

Grief Basics for Kids

some stuff you should know

Learn about Death

Death means that a person's body has stopped working.

- They will not get better
- They cannot feel anything
- They cannot come back
- They did not want to leave you

Learn about Grief

Grief is the word we use to describe how we feel when someone dies.

- We feel all mixed up: sad, mad, scared, lonely, guilty, and sometimes happy
- We don't always feel the same way that others do at the same time
- It is okay to have grief feelings when someone dies
- It is okay to cry and to laugh
- It is still okay to have fun
- It helps to say good-bye

Remember your Loved One

It may help you to do an activity to remember your special person.

- Draw a picture
- Plant a tree
- Go to the cemetery and leave something special
- Write letters to heaven
- Look at photos
- Talk about your memories

Don't Forget: It is smart to ask questions about things you don't understand!

Turn this page over for some ideas to help with your grief.

the Eucalyptus Tree

The Eucalyptus Tree, A program of Cedar Valley Hospice

Cedar Valley Hospice

Draw a circle around the things you are feeling today:

happy

afraid

confused

guilty

mad

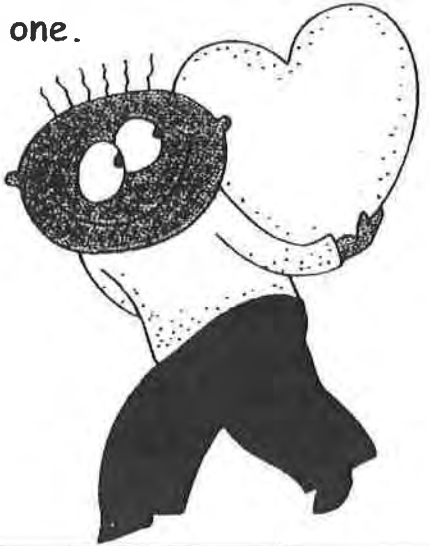
lonely

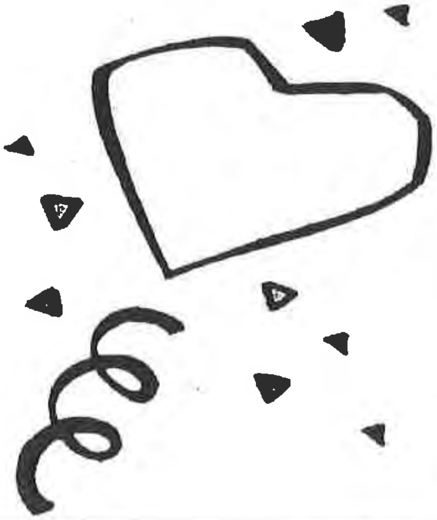
sad

worried

Using the oval, draw a picture of your face and how you look today. Use the second oval to show how you might look on another day.

Think of people you know that you can talk to. Write their names in the hearts below. Share something with one of these people about your loved one.





10 Basic Needs of grieving children

1. **Kids need to learn to mourn.** Dying was a natural part of our lives in times past. Today, people often go to the hospital or leave the home to die. Families may be separated by many miles. Kids are rarely exposed to death unless they live on a farm.

2. **Kids need to mourn small losses.** Teach children about death at the earliest opportunity. If a pet dies, don't replace it right away. Let them feel the pain of the loss. Another good way to teach children about death is to expose them to growing things and explain the life cycle in nature.

3. **Kids need to be informed.** They can see that people are upset. They need to be told why. Don't use euphemisms – use the following terms: death, dead, dying.

4. **Kids need to understand that death is final.** Cartoon images, television, and movies are often the only images that children have. Think about Looney Tunes. Does the Coyote EVER die? NEVER!

5. **Kids need to say good-bye.** Viewing the body and attending the funeral are just as important to a child's process as they are to an adult. There has been an idea that "it's best to let Suzie remember Grandma the way she was when she was alive." This is actually contrary to the mourning and understanding process. Suzie first needs to understand that there has been a death, in order to have positive memories.

6. **Kids need to work out their feelings.** Reading, drawing, playing – all positive ways for children to grieve. Let the kids play at a visitation or wake if it doesn't disturb others.

7. **Kids need reassurance that they will be taken care of.** They need to understand that MOST people live long lives and that someone will always tend to their needs.

8. **Kids need to know that all people will die some day.**

9. **Kids need to be allowed to show their feelings.** We are not always comfortable with children's tears or anger following a death. They need our empathy whether they are happy or sad, or mad or confused.

10. **Kids need their questions answered.** They need to have simple, direct and concise answers in age-appropriate language. Don't be afraid to say, "I don't know."

(Source: Susan Dobie, Associate Professor, University of Northern Iowa)

The Eucalyptus Tree

The Eucalyptus Tree, A program of Cedar Valley Hospice

Cedar Valley Hospice

Grief Basics for Youth

a printable resource for ages 12+

Four Tasks of Grief

Task #1 Believe the reality of the loss.

The first task of grieving is to come full face with the reality that your loved one is dead; that person is gone and will not return.

- Attend the funeral or visitation
- Talk about what happened

Task #2 Experience the pain and emotions.

The second task is to experience the pain and feelings related to your loss. These may include sadness, anger, guilt, loneliness, confusion, relief, and other feelings.

- Grieve and experience your feelings in healthy ways
- Know that it's O.K. to have fun, too

Task #3 Adjust to a life without your loved one.

The third task involves getting used to all the changes involved in life without your loved one.

- Honor your needs for alone time and for time with others
- Be patient—these changes take time

Task #4 Reinvest your energies in life again.

Begin moving on with your own life.

- Start with small steps
- Help someone else

(Adapted from William Worden, 1992)

Ways to Help Yourself Through Grief

Understand what happened. Learn the facts about the death or loss. Learn about the death, grief, and the process of mourning.

Express your emotions in a way that works for you. Some people find that crying, writing in a journal, listening to music, talking to trusted friends, walking or playing sports helps.

Commemorate your loss. You might attend the funeral or memorial service, write a poem or letter, create a scrapbook or memory book, plant a tree, etc. You will probably also share memories informally, tell stories, and spend time with others who knew the person who died.

Seek support from trusted friends or adults. You may want to talk to these people. Other times it might be helpful just to know that they are there or to simply spend time with them.

Make time for solitude and reflection, prayer or inspirational reading.

Communicate with your family. Know that many times they are grieving, too. You may need to be patient with each other. Honesty and openness can help you better understand and support one another.

Ways to Help a Grieving Friend

Tell the person you are sorry about the loss.

Use the name of the person who died. Share a happy memory of the person.

Recognize that everyone grieves differently.
Don't give advice to your friend about what he should be doing.
Be available to listen.

Offer to help catch up on schoolwork or take notes in class.

Treat your friend normally. Invite her to do things. Understand if she chooses not to participate right now.

Give a hug, touch a shoulder, shake hands (as appropriate to your relationship).

Should I Seek
professional help for my child?

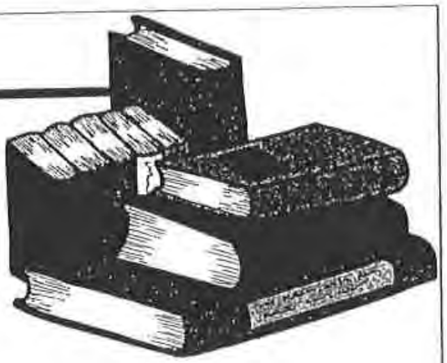
Because grief is so painful and a bereaved child's reactions may be intense, parents and caregivers often wonder when or whether they should seek professional help for their child. Recognizing when additional assistance is needed can be confusing. In general, you know your child best. If you notice behavior that seems out of character for your child, persistent physical complaints, or extreme reactions that you find worrisome, it is wise to consult a professional. The following symptoms and reactions may indicate a need for referral to a physician or mental health professional.

- An extended period of depression, apparent sadness, or loss of interest in daily activities and events
- Prolonged physical complaints that do not have a medical cause
- Loss of appetite or significant or prolonged change in eating habits
- Acting much younger for an extended period of time
- Avoidance of social activities or withdrawal from friends
- Sharp drop in school performance or refusal to attend school
- Inability to relax as they used to; hectic pace or frantic busyness
- Persistent feelings of worthlessness
- Persistent fear or panic or excessive worry
- Repeated statements of a desire to join the dead person or suicidal thoughts
- Drug or alcohol abuse
- Excessively risky behavior
- Chronic anger or hostility
- Other persistent behaviors or symptoms that may be dangerous or interfere with daily functioning at home or school or with friends

(Compiled from the American Academy of Child and Adolescent Psychiatry and Grollman, Talking About Death.)

It is important to remember that grief is a normal reaction to a significant loss. Intense symptoms for a week or two after a major loss are normal and expected. The length and intensity of the behaviors often suggest when to take action. Rabbi Earl Grollman has said that, "The question is not *how* the child is acting, reacting or overreacting but for *how long*" (Grollman, Talking About Death, 1990). **Any behaviors that are dangerous to the child or others are reason to seek professional advice immediately**.

Resources for children & families



Explaining Death to Children

Fall of Freddie the leaf.
Leo Buscaglia. Slack, Inc., 1982.
Gentle willow: A story for children about dying.
Joyce C. Mills. Magination Press, 1993.
Lifetimes: A beautiful way to explain death to children
Bryan Mellonie & Robert Ingpen. Bantam, 1983.
When dinosaurs die: A guide to understanding death.
Laurie Krasny Brown & Marc Brown. Little, Brown & Co., 1996.
When someone dies
Sharon Greenlee. Peachtree, 1992.
Why do people die?
Cynthia MacGregor. Carol Publishing Group, 1999.

For Grieving Children

After Charlotte's mom died.
Cornelia Spelman. Albert Whitman, 1996.
After the funeral.
Jane Loretta Winsch. Paulist Press, 1995.
Don't despair on Thursdays.
Adolph J. Moser. Landmark Editions, 1996.
Everett Anderson's goodbye.
Lucille Clifton. Henry Holt and Co., 1983.
Grandpa loved.
Josephine Nobisso. Gingerbread House, 1989.
I miss you: A first look at death.
Pat Thomas. Barron's, 2001.
Jungle journey: Grieving and remembering Eleanor the elephant.
Barbara Betker McIntyre. Traverse, 2000.
Molly's mom died: A child's book of hope through grief.
Margaret M. Holmes. Centering Corporation, 1999.
Sad isn't bad: A good-grief guidebook for kids dealing with loss.
Michaelene Mundy. One Caring Place, 1998.
Sam's dad died: A child's book of hope through grief.
Margaret M. Holmes. Centering Corporation, 1999.

Someone special died.
Joan Singleton Prestine. Fearon Teacher Aids, 1993.
Thank you, grandpa.
Lynn Plourde. Dutton Children's Books, 2003.
Where is grandpa?
T.A. Barron. Philomel, 2000.

Coping with Cancer

Kemo shark.
H. Elizabeth King. Kidscope, 1995.
Mommy has cancer.
Laura Okmin Russell. Publications International, 2003.
My family is living with cancer.
Sandra Peyser Hazouri & Miriam Smith McLaughlin. mar-co products, 1994.
My mommy has cancer.
Carolyn Stearns Parkinson. Park Press, 1991.
The problem with hair: A story for children who are learning about cancer.
Karen Sue Foss. Centering Corporation, 1996.
Sammy's mommy has cancer.
Sherry Kohlenberg. Magination Press, 1993.
Tickles Tabitha's cancer-tankerous mommy.
Amelia Frahm. Nutcracker Publishing, 2001.
When mommy is sick.
Ferne Sherkin-Langer. Albert Whitman, 1995.

Grieving Teens

Facing change: Falling apart and coming together again in the teen years.
Donna O'Toole, Compassion Press, 1995.
Fire in my heart, ice in my veins (journal).
Enid Samuel Traisman. Centering Corporation, 1992.
Flowers for the ones you've known.
Enid Samuel Traisman. Centering Corporation, 1995.
The grieving teen: A guide for teenagers and their friends.
Helen Fitzgerald. Fireside, 2000.
Healing your grieving heart for teens.
Alan Wolfelt. Companion Press, 2001.
Help for the hard times: getting through loss.
Earl Hipp. Hazelden, 1995.
I will remember you.
Laura Dower. Scholastic, 2001.
Straight talk about death for teenagers: How to cope with losing someone you love.
Earl Grollman. Beacon Press, 1993.

When a friend dies: A book for teens about grieving and healing.
Marilyn E. Gootman. Free Spirit, 1994.

Resources for Adults

Children mourning, mourning children.
Kenneth J. Doka, Ed. Hospice Foundation of America, 1995.
Grief in children: A handbook for adults.
Atle Dyregrov. Jessica Kingsley Publishers, 1991.
The grieving child: A parent's guide.
Helen Fitzgerald. Fireside, 1992.
Helping children cope with grief.
Alan Wolfelt. Accelerated Development Inc., 1983.
Helping children cope with the loss of a loved one: A guide for grownups.
William C. Kroen. Free Spirit, 1996.
How do we tell the children: A step-by-step guide for helping children two to teen cope when someone dies.
Dan Schaefer & Christine Lyons. Newmarket Press, 1993.
Talking about death: A dialogue between parent and child.
Earl A. Grollman. Beacon Press, 1990.

Tear Soup Cooking Tips

Reprinted from
TearSoup, a recipe for healing after loss

If a child is the cook

- Be honest with the child and give simple, clear explanations consistent with the child's level of under standing. Be careful not to overload them with too many facts. This information may need to be repeated many times.
- Prepare the child for what they can expect in a new situation such as, going to a memorial service, or viewing the body. Explain as best you can how others may be reacting and how you would like the child to behave.
- When considering if a child should attend a memorial service consult the child. Their wishes should be the main factor for the decision. Include the child in gatherings at whatever level they want to participate. Helping to make cookies for the reception may be all they want to do.
- Expect them to ask questions like, "Why does he have his glasses on if he's dead and can't read?" Or, "Why is her skin cold?"
- Younger children are more affected by disruptions in their environment than by the loss itself.
- Avoid confusing explanations of death, such as, "gone away", or "gone to sleep." It might be better to say, "his body stopped working."
- Avoid making God responsible for the death. Instead say, " God didn't take your sister, but God welcomed her." Or, "God is sad that we're sad. But now that your sister has died, she is with God."
- Don't assume that if the child isn't talking about the loss it hasn't affected them.
- Be consistent and maintain the usual routines as much as possible.
- Encourage the child to express their feelings and to ask questions.
- Children may act out their grief in their fantasy play and artwork.
- If children have seen adults cry in the past they will be less concerned about tears now.
- Show affection and let them know that they are loved and will be taken care of.
- Each child reacts differently to loss. Behaviors that you may observe include: withdrawal, acting out, disturbances in sleeping and eating, poor concentration, being overly clingy, regression to earlier stages of development, taking on attributes of the deceased.
- Sharing your grief with a child is a way to help them learn about grief.

** To use these tips in your publications or worshops please make sure this byline is included.*

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Portland, Oregon USA
www.griefwatch.com

Dos and Don'ts When Talking to Children About Death

DO

1. Do offer nonverbal support: holding, touching, listening.
2. Do offer answers to questions based on the child's developmental and language level; keep them brief, factual, and simple.
3. Check to see if they heard.
4. Do emphasize the value and quality of their lives and their loved one's.
5. Do reflect on the positive aspects of the deceased.
6. Do answer the repeated questions with patience.
7. Do assure the child he will be loved and cared for.
8. Do let them know the deceased is not suffering.
9. Do let them know they cannot catch what caused the death of the person.
10. Do emphasize the person won't come back.
11. Do answer, "I don't know" when necessary.
12. Do share your own joy in life and views about death and life after death.
13. Do confront fears cognitively.
14. Do help the child avoid models that lead to exaggerated fears.
15. Do let the tears flow - they are like a safety valve.
16. Do aid the child to get out of himself: finger painting, clay modeling, clubs, hobbies, sports.
17. Do encourage the return to daily routines.
18. Do promote the continued respect for the child's personality. Avoid his being placed as an emotional substitute for the deceased. Increased intimacy as in sharing a bedroom may increase his guilt at having the dead parent's mate more to himself.
19. Do act as a model for the business of life being life. Memories should be a constructive force.

DON'T

1. Don't offer an explanation that deviates from your own belief.
2. Don't offer death as sleep or journey.
3. Don't equate death as a reward for being good.
4. Don't present death as a form of punishment.
5. Don't be concerned if the child makes remarks that seem insensitive or macabre.
6. Don't pressure a child to talk about his feelings; share your own feelings and listen.
7. Don't offer sickness as the reason for death.

WARNING SIGNS:
WHEN TO SEEK PROFESSIONAL HELP

Child is stuck in the grief process:

- extreme guilt, denial, disbelief, anger, fear, panic
- negative view of self, world and relationship to it
- continued hostile reaction to deceased or putting deceased on a pedestal
- daydreaming excessively
- marked changes in personality
- trouble with sleeping or sleeping too much
- loss of appetite, becoming withdrawn, anorexic, bulimic
- sudden attacks of delinquency, stealing, or drug involvement
- releasing anger in unhealthy ways toward self and others
- withdrawing and becoming self-isolated

Children may demonstrate some of these behaviors and feelings at the beginning of loss; the key is *intensity* and *duration.*

Child is susceptible to suicide:

- prolonged depression
- threats of suicide
- previous suicide attempts
- irregular eating and/or sleeping habits
- loss of interest in life, school, or job
- giving away possessions or making final arrangements
- marked changes in personality or behavior

The Grief Journey with Children

As adults, most of us wish to spare children the difficulty of going through the painful grieving process. Often parents of young children say their children aren't affected by a loss in the family because "they are too young to understand." On the contrary, children do understand. Children respond to the death of a loved one in different ways. Each response is unique. As adults, we can better serve the grieving needs of our children if we allow them to be the teacher. In so doing, we allow them to share with us their personal journeys through grief.

The following are 14 principles related to the grief journey of children. Following each principle are comments, paraphrased in the voice of a child talking to an adult.

- **1. Allow children to be the teachers about their grief journeys.**

"If you assume you know all about my grief, it's like you don't respect me. The love I had for the person who died was very special and not like anybody else's. And I'm different, too. Nobody else is like me.

"It's all right if you try to understand how I feel, but please don't tell me you know just how I feel, because you don't. All I need is for you to help me find ways to tell you how I feel and for you to really listen to me."

> *"Adults need to remember that physical development doesn't always include emotional maturity."*

- **2. Don't assume every child in a certain age group understands death the same way or has the same feelings.**

"Listen to us and learn from us. Let us be different, even from other kids our own age, in our feelings and understanding.

"After all, we come from different kinds of homes and have different kinds of teachers in different schools. Some of us have parents who pay attention to us, and some of us don't. In some families, there are traditions about how death and grief should be handled. Some of our attitudes have been shaped by those traditions. Some of us are quiet and shy, and some of us talk all the time. Some kids learn faster that others and can remember better. Some kids are scared about death; others just think it's kind of interesting.

"Kids usually understand that grown-ups in their lives are just trying to protect them from hurt. We like that love; but that kind of protection doesn't really help us for very long. Besides, we know you're really trying to protect yourselves, too, when you shut us out of what's going on. Then, we just feel even more confused and alone. And maybe even more afraid, too."

- **3. Healing in grief is a process, not an event.**

"It isn't enough just to tell me that someone I love has died. I need a lot more than that. I really need to have you understand that it will take a long time for me to grieve, and sometimes I will get very tired.

"A lot of adults seem to be telling me to hurry up and get over it, and they want me to be strong;

but I really feel so weak. I just seem to know inside that I will have to face this pain before I can really heal.

"I guess in time I'll be able to accept my life without the person I loved, but I'll never be quite the same as before. It will help me if you'll be patient and let me do that. I need your help to go on in my life, to continue to grow up and find out what my own directions in life should be. After all, you grown-ups don't get over your own grief either, even if you sometimes try to fool yourselves into thinking you do."

■ 4. Don't lie or tell half-truths to children!

"When you lie to me, or tell me only part of the truth, it makes me feel unloved. When you said, 'Grandpa went away on a journey,' I guess you were trying to protect me, but I was confused. Nobody gets that sad because someone went on a trip. Sometimes you don't give us credit for being smart enough or strong enough. We can almost always cope with what we know; it's trying to handle what we don't know that's the big problem.

"If you fib to us, we fill in the empty places with our own ideas. We make up stories to fill in the blanks, and we can think up things that are a whole lot worse than the truth.

"Besides, hiding things from us makes us feel like we've been bad or that we've done something wrong. It also teaches us it's okay not to be honest all the time. So, please tell us the truth, and we'll be honest with you, too."

> *"Reassurance comes from the presence of loving people. Be prepared to reach out and cradle them either physically or emotionally with your empathic presence."*

■ 5. Don't wait for one big tell-all to begin to help children understand death.

"Grown-ups sometimes think kids should reach some magic age before they can teach us anything about death. Well, there isn't any magic age. Actually, we go through losses all the time: friends move away, pets die, teachers and classmates change, sometimes parents get divorced. It's not that we don't understand that loss and change will happen, it's just that we'd rather have the adults we love and trust walk through these experiences with us rather than feel like we have to go through them all alone. Death is a part of life and I'm curious about it. Please teach me."

■ 6. Encourage children to ask questions about death.

"When somebody we love dies, grown-ups need to be open, honest and loving. Please be patient with us when we ask you questions that may not seem important. Remember, our minds don't work the same as yours. Our questions may seem strange, but they are honest. We need to know the answers. When you do answer us, please try to use words we can understand. It's hard for us to make pictures in our minds of things we've never seen.

"Don't worry if you don't have all the answers. It's more important for you to treat our questions with the same respect that you would another adult's than it is for you to know all the right answers.

"We might ask the same questions over and over again. That's natural for us. We can't understand all of it the first time, so every time we ask and you answer, we understand more and more."

■ **7. Don't assume that children always grieve in some kind of orderly and predictable way.**

"We listen to adults talking about the way they handle grief, but the way we feel and talk about our grief can change from day to day. Sometimes, when you don't understand us, you say, 'They are in such-and-such a stage.' But, it's just not that simple. Don't try to get us to some other 'stage' or something. Just let us be where we are.

"You need to remember that no two of us are alike; each of us is different and special, even if we come from the same family. If you try to push us into the "stage" you think we should be in, we probably won't like you very much. maybe you could just follow our lead and let us teach you where we are in our grief. If you could just accept where we are, it would be better."

"It is sometimes difficult to determine whether a child's grief is a reaction to the loss or a mirroring of the grief of those adults surrounding them."

■ **8. Let children know that you really want to understand.**

"Please let us know that you really care about our feelings. Some adults say they feel sorry for us, but that's not what we need.

"We want you to take us seriously enough to let us teach you about our grief. We want you to feel that our thoughts and feelings are important enough for you to want to learn from us. In other words, we want your respect. We need to share our grief without fear of being criticized or abandoned.

"We are sensitive about who really cares and who doesn't. A lot of what we feel from you comes from other than words. Your voice and eye contact are important."

■ **9. Don't misunderstand what may seem to be a lack of feelings when a loved one dies.**

"Sometimes we hurt so much that we don't want to believe someone has died. If we pretend it hasn't happened, then maybe it didn't. This doesn't mean we didn't love the person, it just means we can't absorb all the pain at once.

"There is a difference between what we know in our heads and in what we know in our hearts. The shock of learning about the death of someone we loved is hard. Maybe it's nature's way of protecting us by letting us shut part of it out for a while.

"Sometimes we might go out and play after we learn about the death. Some adults think we are not grieving because we are trying to have fun. Usually, we are just trying to play so it doesn't hurt so much.

"Sometimes adults think we should cry and show our grief all the time. Sometimes, they try to force us to show feelings when we are trying not to feel. Please don't make us hurt so much. We *need understanding, not pressure."*

■ **10. Don't forget about the concept of magical thinking.**

"Sometimes we kids believe that our thoughts can cause things to happen. Most of us have had times when we wished people around us would go away and leave us alone. Then, when someone dies, we often think we caused it to happen because of something we did, thought or said.

"We might blame ourselves for all sorts of stuff we had nothing to do with. Some of us even feel totally responsible for the death, but we can't say anything to anybody about how we feel.

"Talk to us at our level about how the person died. Help us understand that being angry or upset with someone doesn't make him or her die. Even assure us that it was nothing we did that caused the person to die."

■ **11. Remember that feeling relief doesn't mean a lack of love.**

"The person in our lives who died may have been sick a long time. All of our family time seemed to center around the person who was sick. So when that person died, part of us might have been relieved. But just because kids like to have some attention too, please don't think that we didn't love them. We loved them a lot.

"Some adults can't seem to let us talk about these feelings of relief. If we can't talk about our feelings, we sometimes feel guilty for having them. Let us know it's okay to feel this way."

> *"... Grief is a normal expression of love for the person who has died."*

■ **12. Realize that children's bodies react when they experience grief.**

"Our bodies seem to talk to us, sometimes. Especially when sad things happen, like when someone dies.

"When our heads and hearts don't feel good, our bodies don't feel good either. We might feel tired, have tummy aches, sore throats and trouble sleeping. While these things seem to go away over time, we need you to understand.

"Please don't just tell us the sickness is all in our heads. After all, we really do feel sick. We need support and understanding, not judgment.

"You will also find that if you don't let us talk out or play out our grief, our bodies will try to keep telling you what our needs are. We've got to have some way of getting our grief outside of ourselves. If our body problems go on and on, take us to the doctor. Sometimes we really need some medicine, and even if we don't, it will probably reassure both you and us."

■ **13. Don't feel bad when you can't give children total understanding about religion and death.**

"We don't expect you to be able to instantly teach us about faith or religion. You can only share what you believe. Just keep in mind, we have a tough time understanding ideas that don't give us any clear mental pictures.

"Just do the best you can to explain religious beliefs in simple words we can understand.

Sometimes we may have to get older before we can understand everything, but we like it when you care enough to try to help us.

"Don't tell us God needed another 'good' person in Heaven, so He took the person we loved. If you tell us that, we might start being bad so God won't need us the next time!"

- **14. Keep in mind that grief is complicated.**

"We know that dealing with grief is hard work. As we do this work, please let us know that these feelings we have are not something to be ashamed of or something to hide. Remind us in a kind way that grief is a normal expression of love for the person who has died.

"With your love, compassion and understanding, we can all learn from each other. With your help, we can make the experience of grief a valuable time. And thank you for caring. P.S. We love you!"

Excerpted from *A Child's View of Grief* by Dr. Alan Wolfelt

The Adolescent's Mourning Needs

Alan D. Wolfelt, Ph.D.

Editor's note: This article on the special mourning needs of teenagers, as well as the other segments on teen grief in this issue of Centerpiece, are excerpted from Alan's new educational video, "A Teen's View of Grief." We hope this information will help those who counsel bereaved teens better understand the unique challenges of adolescent mourning.

Need 1: Acknowledge the reality of the death

To move toward healing, teenagers must, over time and with the gentle understanding of those around them, acknowledge that someone they love has died and ll not return. Of course, they will me to this new reality in doses as they move from head understanding to heart understanding. As adults, our natural instinct may be to protect young people-and ourselves from such hurtful realities. But remember-teens can cope with what they know. They cannot cope with what they don't know.

As you talk with and listen to the teen, be honest about the nature and cause of death. Teenagers are not immune from magical thinking. They'll sometimes fuel their guilt about the death by literally blaming themselves if they are not helped to reframe this common but devastating feeling. For example, you might hear a teen say, "If I adn't goofed off so much and de her worry, my mom wouldn't have gotten so sick." To be helpful, you must respect the teen's need to express these "if-onlys," but over time help them come to understand the limits of their own culpability.

Need 2: Move toward the pain of the loss

Another important need for teens is to be able to move toward the pain of the loss. This need involves encouraging the young person to embrace all the thoughts and feelings that result from the death. Like the need to acknowledge the reality of death, this need is often bypassed by adults who want to protect young people from pain. Yet, as Helen Keller said years ago, "The only way to get to the other side is to go through the door." Unfortunately, many teens get to the doorway only to have it slammed in their faces.

Grieving adolescents need permission to mourn. Sometimes what they need most from adults is an awareness that it is OK to feel the many emotions they feel and to talk or not talk about those emotions. If you provide a safe harbor, they'll share whatever they need to share, whether that be anger, love, fear, helplessness, hope, guilt or even relief.

Keep in mind that the teen's naturally strong resistance to mourning does not mean the teen isn't hurting inside or isn't capable of mourning with support and understanding. Also remember that because teens don't always articulate their feelings well, they often do as much if not more of their mourning through their behaviors rather than words.

Need 3: Remember the person who died

Another vital need for the bereaved teen is to remember the person who has died. My experience with grieving young people has taught me that remembering makes hoping possible. The process of beginning to embrace memories often begins with the funeral, which offers an opportunity to remember the person who died and affirm the value of the life that was lived.

Many people feel uncomfortable when survivors focus on memories of the person who died or objects that belonged to him or her. Far from being morbid, however, these activities link the teen to the person who died and are valuable and life-affirming.

As you help bereaved teens through their grief journeys, be alert for creative and spontaneous ways to remember the person who died. Journal writing can be particularly helpful for adolescents who may not be ready yet to talk openly about their feelings. When words are inadequate, group rituals like planting a tee or dedicating a plaque can be helpful. These rituals also provide concrete memorials that the teens can revisit long into the future. Finally, keep in mind that remembering can be difficult for teens. Some memories are painful, even frightening. But many are joyful and allow the teen to relive the happy times. A wonderful musical metaphor speaks well to this: "You must listen to the music of the past to sing in the present and dance into the future.

Need 4: Develop a new self-identity

As social beings, we think of ourselves in relation to the people around us. I'm not just Alan Wolfelt, but a son, a brother, a husband, a father. Teenagers may be even more closely linked to those around them than adults are because their self identities are just emerging. So, when someone loved dies, teens must begin the difficult process of forming an identity apart from that person. If her father dies, for instance, the adolescent may no longer be "daddy's little girl." As always, the key here is to allow the teen to express her feelings and not to rush her or rescue her as she struggles with this difficult task of redefining herself.

The death of a family member may also require young people to take on roles that had been filled by the person who died. If younger brother Brian always took out the garbage and then he dies, someone still has to take out the garbage. Taking on this new identity can be very difficult for the teen survivor.

This is not to say that the teenager should never be asked to take on new roles and responsibilities; for the family to go on, everyone must be a part of this redefinition. However, we should never assign inappropriate roles to young people, especially those that force them prematurely into adulthood.

Need 5: Search for meaning

Another important need to stay sensitive to in working with teens is their need to search for meaning. Grieving young people naturally ask "how" and "why" questions about the death of the person they loved. "How could my friend die when she was so young?" or "How can God be good and still allow pain in the world?" are the sorts of questions you may hear.

We can help by letting the bereaved teen know that these kinds of questions are both normal and important. Remember, normalize but don't minimize. But, while it's important to provide an open, caring atmosphere that allows teens to ask these questions, don't think you must always answer them. By acknowledging that we don't know, we ultimately become more helpful to the young person searching for meaning.

You should also note that teenagers sometimes act out their search for meaning. Drunk driving and other behaviors that test their mortality are, unfortunately, common among some bereaved teens. While in general you shouldn't judge the ways in which the grieving young person searches for meaning, life-threatening behaviors obviously require intervention. Don't hesitate to set limits, because in doing so you may literally save a life.

Need 6: Continue to receive support from adults

Another very important need to be familiar with is the ongoing need for bereaved teens to receive support from adults. Grief is a process, not an event, and bereaved adolescents will continue to need the support of helping adults long after the death. You can teach grieving young people that they may experience "grief attacks," or what I call "memory embraces," which are recurring bouts of acute sadness, long into adulthood, and developmental milestones like graduation, marriage and childbirth often bring on grief attacks.

With your help, bereaved teenagers who have all of their mourning needs met will in time heal. I define healing in grief as a softening in the intensity and the duration of painful emotions. This does not mean that the bereaved teen will "recover" from his or her grief, but instead will become reconciled to it. The pain of grief will never disappear completely. Waves of grief may revisit the teen for years and years to come. But with time and love and acceptance, bereaved teens can and do heal.

Working with Bereaved Teens
Do's and Don'ts

Be honest.
Talk openly and honestly with the teen about the death. Remember, teens can cope with what they know. They cannot cope with what they don't know.

Be patient.
Young people need you to be patient with them as they begin to acknowledge the death and search for its meaning. Don't set a timetable for their grief and don't pressure them to get on with thier lives.

Listen without judgement...
Adolescents need you to listen to their feelings. Let them teach you about their own unique grief journeys. Don't decide w' best for them.

...But don't force them to talk.
Listen without judgement, but don't force bereaved teens to talk out their grief if they're not ready. Start with journal writing or other, more private means of mourning.

Help them remember.
Remembering makes hoping possible. Encourage bereaved teens to share their memories, both good and bad.

Let them be teens.
Adolescence is a unique period in a person's life. teens aren't adults and shouldn't be asked to take on adult responsibilities or handle their grief alone.

Educate others.
We as caregivers still have a way to go in educating oureselves about the special needs of bereaved teens. Teach others what you have learned.

Medical
Aspects

MEDICAL ASPECTS OF HOSPICE CARE

OVERVIEW

Hospice care begins with the assessment and management of a patient's physical symptoms. Pain and symptom management, along with an understanding of the underlying disease process, give the patient and family a chance to regain some control in the dying process. This session considers those medical interventions (or non-interventions) that affect the ultimate goal of patient comfort, dignity, and peace of mind.

LEARNING OBJECTIVES

By the end of this session, participants will be able to:

1. Understand that the medical component of the hospice team depends on volunteer observation for a complete picture of patient/family concerns.
2. Have a better understanding of "palliative" or comfort care versus aggressive treatments.
3. Become more familiar with medical terminology.
4. Receive a better understanding of pain control for the hospice patient.

Phyllis Schantz, R.N. and Merry O'Brien, R.N.

OBSERVATIONS ON NUTRITION AND HYDRATION IN DYING CANCER PATIENTS

BACKGROUND

Hospice is not a place, but rather a treatment modality based on professional assistance to the patient and family, who are encouraged to think and act according to their own values and priorities. Hospice providers try to affirm feelings of the patient and family in a non-judgmental fashion. In our hospice setting, very few interventions are used "automatically", instead the attempt is made to individualize treatment. Since many of our patients have become unable to ingest "normal" amounts of fluid and nutrition, we have often had to confront the issues of whether or not to use artificial feeding. The following observations arise from experiences with these patients.

The progression of terminal illness commonly entails certain changes. In the earlier stages, these may be weight loss and weakness, later, increasing fluid deficit, reduced peripheral circulation and possibly an increasing electrolyte imbalance and acidosis may occur. The blood volume and oxygen-carrying capacity may be lower. The patient's level of consciousness often declines toward somnolence and lethargy. Urinary output usually decreases. Skin turgor diminishes, both from dehydration and from depletion of the subcutaneous fat stores. There may be muscular irritability, restlessness, gastrointestinal bleeding, abnormal body temperature and multiple organ failure.

EFFECTS OF DEHYDRATION

Our professional hospice team never unilaterally decides to with hold or withdraw nourishment from any patients, but we allow patients to choose what and when they will eat and drink. This includes those with gastrostomy tubes, nasogastric tubes and intravenous fluids, although many patients coming to hospice have already chosen not to be fed artificially. As intake is spontaneously reduced by the patient, we have noted a reduction of nausea, vomiting and abdominal pain, particularly where there is a bowel obstruction, liver disease, or malignant ascites. Lessened urinary output means fewer linen changes for incontinent patients and less frequent struggling with commode or bedpan for others.

Pulmonary secretions decrease as patients allow themselves to become dehydrated, resulting in less coughing, less congestion and less shortness of breath. With the decrease in mucus, there is less gagging and choking for those with difficulty swallowing and/or extreme weakness. Frequently, the need for oral pharyngeal suctioning is eliminated.

Dehydration can also lead to detrimental effects. Interestingly enough, our patients have not stated that they were thirsty but only that the mouth was dry, a symptom that can easily be relieved by local measures. However, sometimes the symptoms arising from electrolyte imbalances (especially hypercalcemia), such as twitching, muscle spasms, or altered levels of consciousness, require treatment. Sometimes these are best treated with rehydration, but often it is better to use antispasmodics or sedation. Of course, whenever possible, patients' options are made known to them and they are supported in their decisions.

Many patients experience relief and a renewed sense of autonomy from controlling their own intake. When they do not have to force themselves to eat under threat that otherwise tube feeding or intravenous fluids will be started, anxiety diminishes. Frequently, family members have a hard time with the patient's dwindling food intake, as eating represents recovery or at least continuation of life. We find it important to let patient and family move at their own pace in making decisions about nutrition and fluids so that they may come to terms with their impending loss. Among the issues that family members must address is the need to resolve for themselves the symbolic meaning of eating and drinking and of medical means to achieve nutrition and hydration.

GOALS OF THERAPY

Improving nutritional intake, when freely chosen by the patient, increases the patient's sense of well being and improves morale. However, success in developing a plan of care and achieving goals, depends upon the ability of caregivers to acknowledge the patient's unique values and capabilities and to understand the interrelationship of the physical symptoms with the psychological and spiritual distress of dying.

An accurate evaluation of nutritional status depends on obtaining specific data in the context of a more general assessment. A diet history should disclose recent changes in intake, food preferences, dislikes, allergies or intolerances. Specific cultural, socioeconomic and religious factors might dictate diet modifications and explain particular attitudes toward food. Mechanical problems that affect chewing and swallowing, as well as chronic illness, recent surgery or treatment protocols affecting nutrition, are revealed by a careful review of the patient's medical history.

At least weekly, members of the multidisciplinary team will need to update the care plan to reflect the patient's current condition. Our goals at the time of initial general assessment are (1) to appreciate the patient's and the family's understanding of the illness, (2) to explain the concept of hospice care and the capabilities of our program, (3) to focus on the symptoms most distressing to the patient, and (4) to determine the patient's priorities and goals. In this process, we begin to develop a bond of trust with the patient and family. This trusting and supportive relationship among staff, patient and family members is centrally important in the management of nutrition, which we see to involve goals much more important than the normalization of food and fluid intake.

Whenever it might be advantageous to the patient, we discuss both oral and artificially provided food and fluid regimes with the patient and family. Education of patients and families is vital to developing a nutritional care plan that reflects both the patient's goals and his or her physical limitations.

CONTROL OF SYMPTOMS AFFECTING ORAL INTAKE

Decreasing unpleasant symptoms that interfere with nutritional intake is essential. Most of our patients have terminal cancer and chronic pain is frequent. The elimination of pain significantly decreases other symptoms such as fatigue, depression, fear and anorexia.

Many of our patients have disturbances in patterns of elimination. Decreased activity, drug effects and diminished intake contribute to constipation, which must be prevented with stool softeners and laxatives. Diarrhea is uncommon and usually results from the basic illness, from food/fluid intolerance or from enzyme deficiency. A lactose free diet sometimes corrects the food intolerance, while enzyme deficiency malabsorption syndromes respond well to enzyme replacement.

Nausea and vomiting are among the most distressing symptoms for the patient. Contributing factors are many, including disease, drugs, emotions and environment, some of which may be remediable. Frequent small meals and the regular administration of antiemetics such as prochlorperazine (Compazine), either before meals or on an "every four to six hours" schedule, are often effective in relieving nausea. Metoclopramide (Reglan) is sometimes effective if the symptom is caused by decreased gastric and/or intestinal motility. The schedule of care, including treatments and meals, can be adjusted to avoid peak times of nausea and vomiting. Relaxation techniques can be helpful, but providing the patient with the appropriate environment in which to discuss fears and anxieties is most beneficial.

The most frequently neglected part of the alimentary tract is the oral cavity. Dry mouth, stomatitis, infection and dysphagia are both particularly disturbing and usually readily remediable by cleansing the oral cavity and frequently lubricating the membranes. We rely on patient preference in regard to oral hygiene when appropriate. Many commercial preparations are available, but we have had best results with half-strength hydrogen peroxide, diluted with water or normal saline or with baking soda and water. Chewing gum, drinking iced beverages and sucking on hard candy or popsicles can relieve dry mouth. A room humidifier is also helpful when membranes are dry. Viscous lidocaine, offered before meals, will alleviate oral discomfort, but it often alters taste sensations undesirably. Recognition, treatment and relief of these uncomfortable oral symptoms generally improve the patient's self-image as well as his or her intake.

The patient's nutritional status is affected by a number of other conditions, including metabolic disturbances (e.g. hypercalcemia,acidosis), hepatic failure, ascites, hypoxia and changes in mental status. These conditions usually eventuate in death, but they are often temporarily reversible. The risks and benefits of available treatments are weighed, with primary consideration given to the quality of life expected as an outcome. The patient and family are included in the discussion of potential therapy and treatment is initiated or deferred in accordance with the patient's needs and wishes whenever possible.

DIET MODIFICATIONS TO ENCOURAGE ADEQUATE ORAL INTAKE

When a satisfactory level of comfort is reached, many patients experience a renewed appetite for a few weeks or months. A patient's appetite and need for a particular kind of food change with time. Our dietician makes an initial assessment, usually within twenty-four hours of admission and visits regularly throughout the patient's stay. Whatever help the patient may need in order to eat (setting up the tray, arranging the bed, spoon feeding and so forth) is made available by the regular registered nurse staff or a volunteer, helping to make feeding times pleasant and social as well as free of time pressure.

A patient experiencing nausea and vomiting can generally tolerate a bland, nonfatty diet with small meals and snacks to supplement intake. Carbonated beverages, ice and tea in small amounts can be offered even during periods of nausea.

Patients with sore or dry mouth respond favorable to a bland, nonirritating, high-caloric diet with popsicles and ice drinks between meals. Nectars, rather than citrus juices, appeal more to these patients and to patients with dysphagia.

Most dying patients have altered taste sensations. We find the best approach is to listen to the patient and try to provide the foods that are most appealing. Adding flavor enhancers, making extra sugar available or incorporating bitter-tasting food in casseroles are often helpful modifications.

A regular diet, with a minimum of restrictions, is almost uniformly best for dying patients. We have never encountered serious problems allowing a patient free access to salt or fluids. Diabetic patients on regular diet often can be kept symptom free with regular insulin as needed, with only an occasional fasting blood sugar determination to monitor serum glucose levels.

Diet modifications to accommodate the patient's preferences and capabilities are essential to maintaining or improving the patient's nutritional status. A diet that is planned to meet individual needs will contribute much to motivating the patient to enjoy remaining life.

ENHANCING PATIENT MOTIVATION

Our meals are delivered from a central kitchen, but the availability of a refrigerator and microwave oven on the unit permits us to serve patients at a time most comfortable for them.

Patients thus can make decisions regarding time, amount and kind of food. Small meals served more frequently are appreciated.

We have observed that a light meal served in the middle of the night is often therapeutic. Not only does the patient receive added nutritional benefits, but also she or he may be able to discuss concerns and fears with the staff member who joins in a "midnight meal". The late hours, with their absence of distractions are very conducive to just such an exchange. This sort of approach, with each patient's individual concerns being central, usually results in increased interest in nutritional intake.

Occasionally the sight of food can precipitate a negative response. One of our patients, a woman with terminal cancer of the colon, was repulsed by the sight of a full meal. A staff member, having described the menu, would bring her selected small portions, usually one or two tablespoons, which she then consumed slowly and with great relish. Perhaps after enduring multiple surgical and treatment protocols to control her cancer, having this degree of control was important to restoring meaning to her life.

Caregivers should also be attentive to frequently overlooked environmental considerations such as noise, odor and general appearance of the patient's room. Unemptied bedpans, dirty linens or stale air can obviously have an adverse effect on appetite.

Food and water are certainly significant symbols, but the social experience associated with the giving and receiving of food and water may be equally important. The patient receiving intravenous fluids, lying alone in a hospital bed, is having a much less rewarding experience than the patient in a personalized room being given ice chips by a concerned caregiver. Both are receiving water but there are few other similarities. Our policies encourage maximum family participation. The family is encouraged to be present during meals, to feed the patient and to fill out menus. Not only do these practices stimulate patient interest at mealtime, they also help support relationships that are frequently disrupted by chronic illness.

Terminally ill patients may only be able to tolerate small meals. Our efforts are then focused on maximizing intake without significantly increasing the volume. Staff and volunteers exercise imagination to create high-caloric drinks for the patients, using a blender and a number of easily stored and readily accessible ingredients. Eggs, powdered milk, instant breakfast powders, malted milk mixes, fruit and ice cream or sherbet can be blended into flavorful combinations that have wide appeal.

Food craving is a universal experience. Even patients who are not eating often fantasize about foods. A patient may request a particular food and when it is presented, no longer desire it. Disease, drugs or therapy have altered taste to make the item unpalatable or it just isn't as perfect as it was imagined. Caregivers and loved ones might feel rejected if such reactions are not explained to them. Whether or not the food is eaten by the patient, nurturing and caring has taken place. The act of fulfilling the request demonstrates the responsiveness of the caregivers and family to the patient. Is this not nourishment in the broadest definition of the term? Often staff can explain this concept to family members who otherwise are often distraught at the patient's refusal to eat the "favorite foods" they have prepared.

We try to honor all requests and the responses have been very instructive. One patient with cancer of the colon and almost total obstruction was able to tolerate small amounts of ice chips and sips of water and ginger ale. When staff members ordered out for Chinese food on the July Fourth holiday, she became irritated, saying their action was un-American". She asked for a hot dog and potato salad and, while there was justifiable concern by the staff, the request was honored. Not only did she eat it with consummate pleasure, but she retained the meal, much to everyone's surprise and obvious delight. Being open to all possibilities and remaining, non judgmental can clearly lead to unexpected outcomes.

Many people feel that "food is life". A strong emotional attachment to food is sometimes expressed by family members, either through words or actions. Our experience has shown that artificial feeding up until death generally increases patient discomfort, but caregivers need to be tactful and nonjudgmental when discussing this with the patient and family. Involving them in a discussion of the benefits and burdens can allow all involved to determine their real concerns about feeding. Frequently, family members express their inability to cope with their impending loss by demanding forcefeeding. Rather than disagreeing with their demand for feeding the patient, we offer suggestions as to what might be more appropriate and less disturbing for the patient.

WHEN DEATH IS IMMINENT

As the dying process continues, the patient usually becomes less acutely aware of his or her circumstances. The intake of food will no longer be a consideration and hydration becomes the focus. Families may become anxious when they realize death is near. If intravenous feeding is mentioned, team members may need to discuss the risks of intravenous hydration for dying patients. Generally, family members are more concerned about patient comfort than length of life. What they need are reassurances that we know how to provide appropriate care. To provide reassurance and ensure understanding, we review with the family the comfort techniques and hydration measures we envision using. These include frequent mouth care and body lotioning. If the swallowing reflex is intact, we will administer small amounts of water, often using a small syringe. Vaseline will be applied liberally to keep lips moist and a room humidifier will be used. Encouraging family members to participate in this care is especially comforting for them.

We have not seen evidence that hydration occurring at the termination of life results in any pain or distressing experience for the patient. To the contrary, even patients who remain quite alert and communicative become objectively dehydrated without substantial symptoms when treated for dry mouth.

The Issues

ARTIFICIAL FEEDING

Our patients often forgo artificial feeding. However, especially when disruption of nutrition and hydration is abrupt and substantially in advance of death, gastrostomy, jejunostomy, nasogastric tubes or intravenous lines can be employed to provide nutrition while avoiding substantial discomfort to the patient. This becomes a desirable option if the underlying disease would allow a substantial period with a desirable quality of life. The patient should be included in the discussion of the proposed therapy whenever possible.

We prefer to attach the same social significance to artificial feeding as we would to a meal consumed in the natural manner. For example, patients being artificially fed can retain control over their feeding schedule. Controlling "medical" feedings is usually a new and enjoyable experience for the patient. Our patients are surprised to learn that such "treats" as coffee, juice or alcoholic drinks can be put through enteral tubes, as well s the prescribed nourishment. One of our patients who had radical head and neck surgery, described in writing her delight at receiving beer through her gastrostomy tube: "Gee, this is just like a bar, nice and slow."

One patient with pancreatic cancer and widespread liver metastases was admitted with pain, intractable vomiting and diarrhea. He was receiving three thousand calories a day via jejunostomy tube prior to admission. Decreasing this amount significantly reduced the vomiting and diarrhea and proclorperizine and morphine sulfate administered on a regular schedule added to his comfort level. After a discussion with the patient, a feeding schedule was developed that would offer him nourishment by the feeding tube at times when nausea and diminished intestinal motility were least troublesome. He was encouraged to eat (orally) foods of his choice whenever he wished. He was able to eat small amounts several times a day without experiencing significant distress. Several weeks before he died, this patient said, "I feel in control of my life again."

In summary, nutrition and hydration are important and can often be improved, even for dying patients. However, caregivers must be willing to tailor care to the patient, which includes recognizing that force-feeding or artificial feeding can sometimes be harmful and may thus be contraindicated.

CANCER FACTS

CONTROL OF CANCER PAIN

Efforts to relieve pain have been going on for thousands of years. Although many drugs prescribed by modern doctors are based on plants and herbs that were used by ancient peoples to ease pain, a wide variety of pain relief medications is now available. Techniques such as hypnosis and distraction, once used as religious rituals in primitive cultures to exorcise the "evil spirits" that were believed to cause pain, have been refined and improved. Today, major research efforts are continuing to look into the causes of pain and treatments to reduce it.

Cancer is not always accompanied by pain. It is rarely a symptom of early cancer, and advanced cancer patients do not always have pain. But if pain does occur, there are many ways to relieve or reduce it.

What causes pain in people with cancer?

Cancer patients may have pain for a number of reasons, depending on the type of cancer, stage of the disease, and pain threshold (resistance to pain). Cancer pain that lasts a few days or longer may result from:

- Pressure on a nerve by the tumor:
- Infection or inflammation:

- Poor blood circulation because of blocked blood vessels:
- Blockage of an organ or tube in the body:
- Bone fractures caused by cancer cells that have spread to the bone:
- After effects of surgery, stiffness from inactivity, or side effects from medications, such as constipation or mouth sores:
- Nonphysical responses to illness, such as tension, depression or anxiety.

What can be done for such pain?

Whenever possible, the cause of the pain is treated by removing the tumor or decreasing its size. In order to do this, the doctor may recommend surgery, radiation therapy or chemotherapy. Or, the pain itself can be treated without effecting the cancer. Methods for treating pain include medicines, operations on nerves, nerve blocks and techniques such as relaxation, distraction and imagery.

What medicines are used to relieve pain?

Medicines that relieve pain are called analgesics. Analgesics act on the nervous system to relieve pain without causing loss of consciousness. They provide only temporary pain relief because they do not cure the cause of the pain. Analgesics simply suppress pain to a more tolerable level.

Nonprescription pain relievers are used for mild and moderate pain. These analgesics can be bought without a doctor's prescription. Sometimes they are called "over-the-counter" pain remedies. The most common nonprescription pain relievers are aspirin, acetaminophen (Tylenol, Datril), and ibuprofen (Advil, Nuprin). Ibuprofen is one of a new group of pain relievers that has been developed for the treatment of mild to severe pain. These drugs are known as nonsteroidal anti-inflammatory agents. The 200 mg. strength of ibuprofen is available without a prescription. Larger doses of this drug as well as most other nonsteroidal anti-inflammatory drugs (Motrin, Dolobid, Nalfon, Anaprox, Feldene, Clinoril) must be ordered by your doctor. Because these drugs are not narcotics, their use does not result in drug tolerance or physical dependence. Other non-narcotic prescription drugs are effective for relieving muscle pain in cancer patients.

Most prescription pain relievers are narcotics, drugs that have the ability to relieve pain and cause drowsiness or sleep. All narcotics have similar side effects and may be habit forming.

Narcotic pain relievers include:

codeine
hydromorphone (Dilaudid)
levorphanol (Levo-Dromoran)
meperidine (Demerol)
methadone (Dolophine)
morphine
oxycodone (in Percodan)
oxymorphone (Numorphan)
pentazocine (Talwin)
propoxyphene (Darvon)

These pain relievers can be obtained only with a doctor's written prescription. They may be taken by mouth (orally, PO), by injection (intramuscularly, IM), through the vein (intravenously, IV) or by rectal suppository, although not all narcotics come in all these forms. These drugs are used alone or with nonprescription pain relievers to treat moderate to severe pain.

Does the use of narcotics cause addiction?

Fear of addiction is very common among people who must take narcotics for pain relief. Many people use the term "addiction" without understanding exactly what it means - the compulsive use of habit forming drugs to satisfy physical, emotional and psychological needs rather than for medical reasons. Drug addiction in patients with cancer pain can occur, but it is not a major problem. As long as narcotics are used under proper medical supervision, the chance of addiction is small. Most patients who take narcotics for pain relief can stop taking these drugs if their pain can be controlled by other means. If narcotics are the only effective way to relieve pain, the patient's comfort is more important than the possibility of addiction.

What is drug tolerance?

Persons who take narcotics for pain control sometimes find they have to take gradually larger doses over a period of time to relieve their pain. This may be due to an increase in the pain or to the development of drug tolerance. When narcotics are taken regularly, the body doesn't respond to them as well as it once did and these drugs become less effective. Larger or more frequent doses must be taken to obtain the effect that was achieved with the original dose. Increasing the doses of narcotics to relieve increasing pain or to overcome drug tolerance is not addiction, although it may lead to physical dependence on the drugs.

How are medicines best used to relieve pain?

A preventive approach - staying "on top" of the pain - is the best way to control pain and may actually require lower doses of pain reliever. For pain present to some degree throughout the day, medicine should be taken on a scheduled basis to prevent the pain from getting worse. Taking a mild pain reliever three to four times a day on a regular schedule, rather than waiting for the pain to return may be enough to control pain.

What are some nonmedical ways to treat pain?

Some ways to relieve pain without using medicine include relaxation, imagery, distraction and skin stimulation.

Relaxation has been found to relieve pain or keep it from getting worse by reducing the tension in the muscles. It can promote sleep, give more energy, combat fatigue, reduce anxiety and make other pain relief methods work better.

Imagery is using imagination to create mental pictures or situations. When used to relieve pain, imagery can be thought of as a deliberate daydream or self-hypnosis.

Distraction means turning one's attention to something other than the pain. Many people use this method without knowing it when they watch television or listen to the radio to "take their mind off" the pain. Any activity that occupies attention can be used for distraction.

Skin stimulation is the use of pressure, friction, temperature changes, chemical substances or mild electrical current to excite the nerve endings in the skin. Scientists believe that the same nerve pathways transmit the feeling of pain, heat, cold and pressure to the brain. When the skin is stimulated so that pressure, warmth or cold is felt, pain sensation is lessened or blocked.

Are there any other pain relief methods?

Other medicines: Other types of drugs can be taken with analgesics to help control pain, though not all patients will benefit from them. Antidepressants, tranquilizers, cortisone and alcohol are some the drugs that might be useful.

Surgical methods: Pain cannot be felt if the nerve pathways that relay pain impulses to the brain are blocked. To block these pathways, a neurosurgeon may cut a nerve close to the spinal cord (rhizotomy) or cut bundles of nerves in the spinal cord itself (cordotomy).

Nerve blocks: When certain substances are injected into or around a nerve, that nerve is no longer able to transmit pain. A local anesthetic, which may be combined with cortisone, provides temporary pain relief. For longer-lasting pain relief, phenol or alcohol can be injected. Loss of all feeling in the affected area is a frequent side effect of a nerve block.

Transcutaneous electric nerve stimulation (TENS or TNS): This is a technique of skin stimulation in which mild electric currents are applied to certain areas of the skin by a small power pack attached to two electrodes. The sensation is described as a buzzing, tingling or tapping feeling; it does not feel like a shock. The small electric impulses seem to block incoming pain sensations.

Biofeedback: With the help of special machines, people can learn to control certain body functions such as heart rate, blood pressure and muscle tension. Biofeedback is sometimes used to help people learn to relax. Cancer patients can use biofeedback techniques to reduce anxiety in order to help them cope with their pain. Biofeedback may be used along with other pain-relief methods.

Acupuncture: In acupuncture, special needles are inserted into the body at certain points and at various depths and angles. Particular groups of acupuncture points are believed to control specific areas of pain sensation. The procedure has been used in China and elsewhere to treat many types of pain and as an anesthetic, but its usefulness for cancer patients has not been proven.

Hypnosis: No one knows how hypnosis works to control pain. Hypnosis is a trance-like state that can be induced by a person trained in special techniques. During hypnosis a person is open to suggestions made by the hypnotist. To relieve pain, the hypnotist may suggest that when the person "wakes up", pain will be gone. Some cancer patients have learned methods of self-hypnosis that they use to control pain. However, the effectiveness of hypnosis for pain relief is unpredictable.

What if pain is not relieved and the doctor says nothing more can be done?

No one doctor can be expected to know everything about all medical problems. Pain management for cancer is a rather new field. New techniques have been developed in the last few years. Pain specialists such as oncologists, anesthesiologists, other doctors, nurses and pharmacists are available for consultation. Below is a list of sources that can provide names of specialists or pain programs in local areas.

* American Pain Society
Suite 925
1615 L Street NW.
Washington, D.C. 20036

* International Association for the Study of Pain
Suite 306
909 Northeast 43rd Street
Seattle, Washington 98105

* National Hospice Organization
Suite 307
1901 North Fort Meyer Drive
Arlington, Virginia 22209

* The oncology department in a hospital or medical center

- The local unit of the American Cancer Society listed in your telephone directory. The American Cancer society can also provide more information about pain control in a booklet called <u>**QUESTIONS AND ANSWERS ABOUT PAIN CONTROL**</u>

For additional information on this subject and for other NCI publications, write to the Office of Cancer Communications, National Cancer Institute, Bethesda, Maryland 20892 or call the Cancer Information Service at: 1-800-4-CANCER.

In Alaska call 1-800-638-6070: in Hawaii, on Oahu, call 524-1234 (call collect from neighbor islands). Spanish-speaking staff members are available to callers from the following areas (daytime hours only): California, Florida, Georgia, Illinois, New Jersey (area code 201), New York and Texas.

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CTRLCAPN

CANCER WORD BOOK

A

Antibiotic/ A substance produced by living organisms such as bacteria, or molds, which can destroy other bacteria. Penicillin is the most familiar example. Some antibiotics have shown effective anticancer activity.

Antibody/ A substance, formed by the body as a reaction to a foreign agent or antigen. The antibody formed, works only against that particular antigen.

Antigen/ Any foreign substance which causes the formation of antibodies as protective substances in the body.

Axilla/ The armpit; axillary nodes are located in the cavity beneath the shoulder.

B

Barium Enema/ The use of barium sulfate, introduced into the intestinal tract by an enema to allow X-ray exam of the lower bowel.

Basal Cell Carcinoma/ The most common type of skin cancer. It forms in the lowermost layer of the skin, grows slowly and seldom spreads. It is easily detected and readily cured when treated promptly.

Benign Tumor/An abnormal swelling or growth that is not a cancer and is usually harmless.

Biochemistry/ The study of the chemical structure and the chemical function of all living organisms.

Biopsy/ The surgical removal of a piece of tissue from a living subject for microscopic examination to make a diagnosis,e.g. to determine whether cancer cells are present.

Blood Count/ An examination of the blood to count the number of white and red blood cells and platelets.

Breast Self-Examination/ Simple procedure to examine breasts thoroughly, recommended once a month for all women to do themselves between regular physician checkups.

C

Cancer/ A large group of diseases characterized by uncontrolled growth and spread of abnormal cells.

Carcinogen/ Any substance that causes cancer.

Carcinoma/ A form of cancer which arises in the tissues that cover or line such organs of the body as skin, uterus, lung, intestines, breasts, etc.

Carcinoma in Situ/ A stage in the growth of cancer when it is still confined to the tissue in which it started.

Cell/ The basic structural unit of life.

Cervix/ Any neck or neck-like structure in the body;in cancer terminology it usually refers to the neck of the uterus.

Chemotherapy/ Treatment of disease by chemical compounds.

Clinical/ Pertaining to the study and treatment of disease in human beings by direct observation, as distinguished from laboratory research.

Colon/ The part of the large intestine that extends from the end of the small intestine to the rectum.

Colonoscopy/ Technique for direct visual examination of the entire large bowel by means of a lighted, flexible tube.

Colostomy/ A surgical procedure which creates an artificial opening from the colon through the abdominal wall in order to permit elimination or wastes.

Colposcopy/ Examination of the vagina and cervix with a magnifying instrument called a colposcope to check prestained tissues for abnormality.

Combination Therapy/ The use of two or more modes of treatment-surgery, irradiation, chemotherapy, immunotherapy-in combination, alternately or together, to achieve optimum results against cancer.

Cytology/ The science which deals with the study of living cells. Cells which have been sloughed off, or scraped off, from such organs of the body as uterus, lungs, bladder or stomach are examined uner the microscope for early signs of abnormality. The pap test used for early detection of cervical cancer is an example of this method; also referred to as exfoliative cytology.

Cyst/ An abnormal sac which contains a liquid or semisolid material; may be bengin or malignant.

D__________________________

Diagnosis/ Identifying a disease by it's signs, symptoms, course and laboratory findings.

E__________________________

Endometrial/ Having to do with the lining of the uterus or body of the womb, used in describing a form of uterine cancer.

Enterostomal Therapist/ An allied health professional trained in the care of stomas, or openings in the abdominal wall, constructed to permit the elimination of wastes from the digestive or urinary tracts.

Enzyme/ A complex organic compound produced in the body capable of speeding up a particular chemical reaction.

Epidemiology/ The study of incidence, distribution, environmental causes and control of a disease in a population.

Esophageal Speech/ An acquired technique by which "larngnectomee,"(those who have lost their voice boxes)are taught to speak again by swallowing and expelling air through the mouth from the esophagus (gullet).

Estrogen/ A hormone secreted by the ovaries which is essential to reproduction; involved in the menstrual cycle; produces female secondary sex characteristics, such as breast development.

Etiology/ The study of the causes of disease.

Excision/ Surgical removal of a diseased part of the body, including cancerous growths.

Excoriation/ Break in skin surface,usually covered with blood or serous crusts.

G

Genes/ The hereditary units of life which control the cells transfer of a trait or process.

Guaiac Test/ A chemical test used to detect occult (hidden) blood in the stool. A simple method allows stool specimens to be placed on special guaiac-treated paper slides. These slides are then treated and checked by a doctor or lab technician. The test is well suited to screening programs for colon-rectal cancer because the specimen can be prepared at home.

H

Hodgkin's Disease/ A form of cancer that affects the lymphatic system, the network of glands or nodes and vessels which manufactures and circulates lymph throughout the body to fight infection.

Hormones/ Chemcicals that help regulate the body mechanisms including growth, metabolism and reproduction.

Hormonotherapy/ Treatment by the use of hormones; used in controlling cancers in conjunction with other modalities such as chemotherapy.

Hysterectomy/ A surgical procedure for removal of the uterus; may be combined with removal of ovaries (oophorectomy).

I

Ileostomy/ A surgical procedure which constructs an artificial opening of the small intestine through the abdominal wall for elimination of body wastes.

Immunology/ Branch of science dealing with the body's resisttance mechanism against disease or the invasion of a foreign substance.

Immunotherapy/Treatment of disease by stimulating the body's own defense mechanism against the disease.

L

Laryngectomy/ A surgical procedure which removes the larynx or voice box. A largngectomee is someone who has undergone this surgery.

Lesion/ Describes any abnormal change in tissue due to disease or injury.

Leukemia/ Cancer of the blood-forming tissues (bone marrow, lumph nodes, spleen); characterized by the over-production of white blood cells.

Lymph/A clear fluid which circulates throughout the body, containing white blood cells called lymphocytes, antibodies and nourishing substances.

Lymph Gland/ Tissue which is made up of lymphocytes and connective tissue and produces lymph and lymphocytes. These lymph glands, or nodes, normally act as filters of impurities in the body.

Lymphedema/Swelling as a result of obstruction of lymphatic vessels or lymph nodes.

Lymphoma/ Malignant growths of lymph nodes.

M

Malignant Tumor/ A tumor made up of cancer cells. These tumors continue to grow and invade surrounding tissues; cells may break away and grow elsewhere. (See Benign Tumor, Metastasis).

Mammography/ Low-dose X-ray technique for studying the structure of breast tissue in order to locate any abnormality at the earliest possible stage; permits detection of a breast cancer before the lump can be felt.

Mastectomy/ Surgical removal of a cancerous breast to prevent spread of the disease. Simple mastectomy refers to removal of the entire breast. Radical Mastectomy involves removal of the entire breast, underlying muscle tissue and lymph nodes in the armpit. A mastectomee is someone who has had the breast removed.

Melanoma/ A pigmented, highly malignant form of cancer of the skin. The tumor may vary in color from nearly black to almost white.

Metastasis/The process by which cancer cells break away and spread to other places in the body by way of the lymph and blood systems and start new malignant tumors.

Mitosis/ The process of cell reproduction by which new cells are formed.

N

Neoplasm/ Any new, abnormal growth of cells or tissue; may be benign or malignant but is customarily used to describe a cancerous tumor.

O

Oncology/ The study of cancer, which has become a specialty branch of modern medicine.

Ostomy/ A surgical procedure that creates a stoma, or artificial opening. A stoma of the intestinal and urinary tracts permits the elimination of wastes through the abdominal wall. A stoma of the respiratory tract permits the passage of air through the neck. An "ostomate" is someone who has had this form of surgery.

P

Palliative Treatment/ Providing relief from symptoms of a disease but not directly curing the disease; alleviating pain.

Palpation/ A detection procedure using the hands to examine organs without the aid of instruments.

Pap Test/ Developed by the late Dr. George Papanicolaou, to examine, under the microscope, cells found in vaginal secretions. Its major purpose is to detect cancer of the cervix in its earliest stage. (see Cytology).

Pathology/ The science which studies the nature, cause and development of disease through examination of tissues and fluids of the body. A pathogogist does autopsies and examines urine, blood, tissues removed for biopsies, etc.

Pelvic Examination/ Examination of the organs of the pelvis, through the vagina and rectum.

Platelets/ A small circular or oval disk present in the blood which is necessary for the ability of the blood to clot.

Pneumonectomy/ A surgical procedure for removal of an entire lung.

Polyp/ An over growth of tissue projecting into a cavity of the body, e.g., the lining of the colon, the nasal passage, or the surface of vocal cords.

Procto/ Short for Proctosigmoidoscopy, examination of the first 10 inches of the rectum and colon with a hollow, lighted tube.

Prognosis/ Prediction of the course of a disease and the future prospects for the patient.

Prostate/A gland located at the base of the bladder in males.

Prosthesis/ An artificial replacement for a missing body part, e.g., reast, leg, arm, eye.

Protocol/ Standardized procedures followed by physicians so that results of treatment of different patients can be compare.

Q

Quackery/ The practice of using untested or unproven methods of treatment for a disease; alleged recoveries cannot be validated or equaled in subsequent tests under controlled situations.

R

Radiation Therapy/ Treatment of cancer with radiant energy of extremely short wave lengths which damages or kills cancer cells. Radioactive elements such as cobalt 60, radium and radon, gallium and Cesium 27 are used to produce gamma rays. Supervoltage machines, such as betatrons and linear accelerators are used as sources of X-rays.

Radiologist/ A physician with special experience using radiant energy in the diagnosis and treatment of disease.

Regional Involvement/ When cancer has spread from it's original site to nearby areas. (See Metastasis)

Remission/ Complete or partial disappearance of the signs and symptoms of a disease; or the period during which a disease is under control.

S

Sarcoma/ A form of cancer that arises in the connective tissue and muscles, such as bone and cartilage.

Sputum Test/ A study of cells from the lungs contained in material coughed up in the sputum.

Staging/ Determining the extent of growth of a cancer so that results of treatment can be compared and prognosis offered.

T

Therapy/ The treatment of disease.

Thermography/ A technique for measuring the surface temperature of parts of the body to detect underlying disease; used along with mammography and palpation for discovering breast cancer in it's earliest stage.

Tissue/ A collection of similar cells. There are four basic tissues in the body: 1) epithelial 2) connective 3)muscle 4) nerve.

Tracheostomy/ A surgical procedure to create a stoma or permanent opening of the trachea or windpipe through the neck. Tracheostomy is the surgery that temporarily provides direct passage of air into the windpipe.

Tumor/ A swelling or enlargement; an abnormal mass, either benign or malignant, which performs no useful body function.

U

Unproven Methods/ Untested drugs or worthless remedies to treat cancer. (See Quackery)

Urostomy/ A surgical procedure which creates a stoma or opening in the urinary tract through the abdominal wall to permit the elimination of urine.

Uterus/ Organ in the female for receiving the fertilized egg and nourishing the embryo development prior to birth.

V

Virology/ The branch of biology dealing with the study of viruses.

Virus/ A tiny living parasite which invades cells and alters their chemistry so that the cells are compelled to produce more virus particles. Viruses cause many diseases.

W

Wilms' Tumor/ A form of cancer of the kidney which affects young children primarily.

X

Xeroradiography/ A photographic way of recording X-ray images; useful in detecting breast cancer early.

X-ray/ Radiant energy of extremely short wave length, used to diagnose and treat cancer.

Communication

COMMUNICATION/COMPANIONING

OVERVIEW

This session focuses on the volunteer's personal interaction with the patient/family. Active listening and effective verbal and non-verbal responses to questions are essential communication skills. The concept of "companioning" as a tool for the caregiver will be explored.

LEARNING OBJECTIVES

By the end of this session the participants will be able to:

1. Identify and use specific skills communicating with terminally ill patients and their families.
2. Apply active listening skills in responding to questions or comments by the patient/family.
3. Respond appropriately to the expression of feelings by the patient/family.
4. Understand and use the concept of "companioning."

Listen

by Author Unknown

When I ask you to listen to me and you start giving advice,
you have not done what I asked.

When I ask you to listen to me and you begin to tell me why I shouldn't feel
that way, you are trampling on my feelings.

When I ask you to listen to me and you feel you have to *do* something to solve
my problem, you have failed me, strange as that may seem.

Listen! All I asked was that you listen.
Not to talk or do - just hear me.
Advice is cheap. Ten cents will get you both Dear Abby and Bill Graham in the
same newspaper.
And I can do for myself. I'm not helpless.
Maybe discouraged and faltering, but not helpless.

When you do something for me that I can and need to do for myself,
you contribute to my fear and weakness.

But, when you accept as a single fact that I do feel what I feel,
no matter how irrational, then I can quit trying to convince
you and get to the business of understanding what's
behind this irrational feeling.

And when that's clear, the answers are obvious
and I don't need advice.
Irrational feelings make sense when we understand
what's behind them.

So, please listen and just hear me. And if you want to talk,
wait a minute for your turn; and I'll listen to you.

ACTIVE LISTENING TECHNIQUES

1. Show external signs of listening by eye contact, nodding appropriately, smiling, gestures, posture.
2. Ask open-ended questions: "help me understand" or, "what do you mean?"
3. Ask questions that clarify what the other person wants to communicate, not what you hope he is leading up to.
4. Allow time for silence and thought; calm silence helps to build trust.
5. Observe signals that a person wants to talk: leaning forward, seeking eye contact with you, pursing their lips; invite them to talk.
6. Listen within the framework of the other person's purpose; seemingly light social conversation may be leading to a concern or it may also be a need for a light social conversation.
7. As you listen to the words, be equally aware of the person's nationality, race, religion, experience, conditioning, and feelings.
8. Use words the speaker uses insofar as possible.
9. Especially when the person is expressing only incomplete ideas, repeat the gist of what he says so he can continue further if he wants to.
10. If words expressing feelings are use, form a question such as, "you said that made you feel "alone"; what do you mean?" Allow the person to expand or not, as he chooses.

ATTENDING

Helping as a caregiver, demands a certain physical presence. This presence, this "being with" a person is what is meant by attending.

The skills of ATTENDING can be summarized using the acronym SOLER. SOLER is a non-verbal listening technique used in communication. SOLER reminds us that five basic components of non-verbal communication can improve the listening process.

Squarely

Face the individual **squarely**
Get in a straight line (if possible) with the person
Get at the same height or eye-to-eye level
Be within arm's length (both you and the other person's arms) - watch personal space

Open

Adopt an **open** posture
Be aware of placement of hands, legs, body (i.e. don't fold arms or cross legs)

Lean

Periodically **lean** toward the person - again watch personal space
Give the person your total attention

Eye

Maintain good **eye** contact
Regular but varied eye contact

Relax

Maintain a **relaxed** appearance and manner
Try to be relaxed while engaging in above behaviors

Gerard Egan, PhD, a Professor of Organization Development and Psychology is credited with developing the SOLER listening technique.

Nearing Death Awareness

From *Final Gifts: Understanding the Special Awareness, Needs, and Communications of the Dying,* by Maggie Callanan and Patricia Kelley

There are a few specific reminders that will help you recognize, understand, and respond to Nearing Death Awareness:

- Pay attention to *everything* the dying person says. You might want to keep pens and a spiral notebook beside the bed so that anyone can jot down notes about gestures, conversation, or anything out of the ordinary said by the dying person. Talk with one another about these comments and gestures.
- Remember that there may be important messages in *any* communication, however vague or garbled. Not every statement made by a dying person has significance, but heed them all so as not to miss the ones that do.
- Watch for key signs: a glassy-eyed look; the appearance of staring through you; distractedness or secretiveness; seemingly inappropriate smiles or gestures, such as pointing, reaching toward someone or something unseen, or waving when no one is there; efforts to pick at the covers or get out of bed for no apparent reason; agitation or distress at your inability to comprehend something the dying person has tried to say.
- Respond to anything you don't understand with gently inquiries. "Can you tell me what's happening?" is sometimes a helpful way to initiate this kind of conversation. You might also try saying, "You seem different today. Can you tell me why?"
- Pose questions in open-ended encouraging terms. For example, if a dying person whose mother is long dead says, "My mother's waiting for me," turn that comment into a question: "Mother's waiting for you?" or "I'm so glad she's close to you. Can you tell me about it?"
- Accept and validate what they dying person tells you. If he says, "I see a beautiful place?" say, "That's wonderful! Can you tell me more about it?" or "I'm glad you're telling me this. I really want to understand what's happening to you. Can you tell me more?"
- Don't argue or challenge. By saying something like, "You couldn't possibly have seen Mother, she's been dead for ten years," you could increase the dying person's frustration and isolation, and run the risk of putting an end to further attempts at communicating.

- Remember that a dying person may employ images from a life experiences like work or hobbies. A pilot may talk about getting ready to go for a flight; carry the metaphor forward, "Do you know when it leaves?" or "Is there anyone on the plane you know?" or "Is there anything I can do to help you get ready for takeoff?"

- Be honest about having trouble understanding. One way is to say, "I think you're trying to tell me something important and I'm trying very hard, but I'm just not getting it. I'll keep trying. Please don't give up and me."

- Don't push. Let the dying control the breadth and depth of the conversation - they may not be able to put their experiences into words; insisting on more talk may frustrate or overwhelm them.

- Avoid instilling a sense of failure in the dying person. If the information is garbled or the delivery impossibly vague, show that you appreciate the effort by saying, "I can see that this is hard for you; I appreciate your trying to share it with me," or "I can see you're getting tired/angry/frustrated. Would it be easier if we talked about this later?" or "Don't worry. We'll keep trying and maybe it will come."

- If you don't know what to say, don't say anything. Sometimes the best response is simply to touch the dying person's hand, or smile and stroke his or her forehead. Touching gives the very important message, "I'm with you." Or you could say, "That's interesting, let me think about it."

- Remember that sometimes the one dying picks an unlikely confidant. Dying people often try to communicate important information to someone who makes them feel safe - who won't get upset or be taken aback by such confidences. If you're an outsider chosen for this role, share the information as gently and completely as possible with the appropriate family members or friends. They may be more familiar with innuendos in a message because they know the person well.

An Alzheimer's Plea

The song of the birds, I cannot hear,
The flowers, I cannot smell.
I cannot remember, the ones that I loved,
And things that I knew so well.
I cannot see the wondrous sights.
My eyes can no longer see,
The setting sun, the stars at night,
The beauty of a tree.
I cannot cry, I have no tears,
And yet my heart is filled with fears.
I cannot speak as I did before,
My voice has faded away.
I'm in a world all of my own,
I cannot even pray.
I know no difference between day and night,
Time means nothing to me,
I cannot tell the wrongs from right,
Oh! God, what has happened to me?
I long to feel the tender touch,
Of someone to light the way,
Someone to lead me out of my world,
And turn the night into day.
I need a strong and gentle hand,
Someone who understands,
Someone who would guide me,
Out of these strange and distant lands.

~Fred A. Das

How to Communicate Caring to Your Unresponsive Patient

One of the most challenging types of support is the care of an unresponsive person. How can you know that you are "connecting?"

Here are five ways that you can let an unresponsive patient know that their needs and feelings are important.

1. **Speak quietly and naturally.**
   The last sense to leave is hearing and, unless the person was hard of hearing before they became unresponsive, they can hear you. A soft, steady voice communicates respect and comfort.

2. **Stay close, offering a loving presence.**
   Touch is important, but be aware of how you touch. The head is a very private part of the body. Don't put your hands on top of the patient's head or shoulders. This can feel oppressive to the person, especially if they have a history of abuse.

3. **Provide soothing music.**
   Musical is a language that transcends barriers of all kinds, creating an atmosphere of peace and tranquility to help the patient feel safe. Ask your Gilchrist Hospice Care Music Therapist for suggestions of appropriate music.

4. **If the patient is restless, place something in their hands to feel.**
   A stuffed animal can be soft and comforting to touch. Something with an unusual texture can give them something to focus on when they can't otherwise communicate with their environment.

5. **Pay attention to the physical environment.**
   If you or I get too warm, we can shed a sweater. A bedfast, unresponsive patient doesn't have the luxury of adjusting to the environment. Pay attention to temperature, light levels, smell, and the noise factor. Make sure every facet of the environment supports safety and comfort for your patient.

Border Mountain, PO box 1372, Mountain Home, Idaho 83647 503-774-4658
bordermountain@msn.com www.bordermoutnain.com

CARE GIVER'S BILL OF RIGHTS

IT IS ALL RIGHT TO:

1. **Be Angry**
   - Turn this energy into positive action. Clean closets, take a walk, and talk with someone.
2. **Be Frustrated**
   - Stop the present activity, take a deep breath and begin a different activity.
3. **Need Time Alone**
   - A favorite chair in a quite room, a trip to the store or out with friends.
4. **Need and Ask For Help**
   - Explore family, friends, local agencies for services needed. Most doctors' offices and clergy can make referrals.
5. **Trust Your Judgment**
   - Relax; you are doing the best you can.
6. **Recognize Your Limits**
   - You are a valuable person; take care of your self, too!
7. **Make Mistakes**
   - So, who's perfect? This is how we learn.
8. **Grieve**
   - This is a normal response to a loss. You may be sad over the loss of the way things were.
9. **Laugh and Love**
   - It can seem out of place, but your capacity to feel is not gone and can occur unexpectedly.
10. **Hope**
    - Tomorrow, the day may go smoother, a friend may call, and a cure may be found.

Communication Highlights

I. Be aware of cultural and spiritual differences. Set aside your personal belief system - be open to new ideas and new ways of approaching communication.
   - A. Non-verbal
      - 1. Eye contact
      - 2. Personal Space
      - 3. Imitation of mannerisms and speech pattern and tone
   - B. Verbal
      - 1. Don't stereotype - watch assumptions
      - 2. Examine your own feelings about lifestyles that are different
         - a. AIDS
         - b. Drug Abuse
         - c. Alcoholism
   - C. Your responses to patient/family must be non-judgmental

II. Be honest with yourself first - do not accept a case that has emotional or prejudicial circumstances you can't handle objectively.

III. Best companion advice
   - A. Mouth closed
   - B. Ears open
   - C. Be available

IV. Helpful opening line
   - A. "What are your worries?"

V. Best answer to any question
   - A. "I don't know."

VI. Best thing to know
   - A. You can't assume anything

VII. Best response to "why?"
   - A. "I don't know, but what can I do to help you through today."
   - B. "Why" doesn't really matter - but honor the "whys"
   - C. "I know you're frustrated by the absence of answers."

A Perspective on Cultural Diversity

If we could shrink the earth's population to a village of precisely 100 people, with all the existing human ratios remaining the same, it would look something like the following:

There would be:

- 57 Asians
- 21 Europeans
- 14 from the Western Hemisphere, both north and south
- 8 Africans
- 52 would be female
- 48 would be male
- 70 would be non-white
- 30 would be white
- 70 would be non-Christian
- 30 would be Christian
- 89 would be heterosexual
- 11 would be homosexual
- 6 people would possess 59% of the entire world's wealth and all 6 would be from the US
- 80 would live in substandard housing
- 70 would be unable to read
- 50 would suffer from malnutrition
- 1 would be near death & 1 would be near birth
- 1 (yes, only 1) would have a college education
- 1 would own a computer

When one considers our world from such a compressed perspective, the need for both acceptance, understanding and education becomes glaringly apparent.

The following is something else to ponder…If you woke up the morning with more health than illness…you are more blessed than the million who will not survive this week.

If you have never experienced the danger of battle, the loneliness of imprisonment, the agony of torture, or the pangs of starvation…you are ahead of 500 million people in the world.

If you have food in the refrigerator, clothes on your back, a roof overhead and a place to sleep…you are richer that 75% of the world.

If you have money in the bank, in your wallet, and spare change in a dish someplace…you are among the top 8% of the world's wealthy.

If your parents are still alive and married…you are very rare, even in the United States and Canada.

If you can read this message, you just received a double blessing in that someone was thinking of you, and furthermore, you are more blessed than over two billion people in the world that cannot read at all.

-Source unknown

WAYS TO DEVELOP CULTURAL SENSITVITY

1. Recognize that cultural diversity exists
2. Demonstrate respect for people as unique individuals, with culture as one factor that contributes to their uniqueness.
3. Respect the unfamiliar
4. Identify and examine your own cultural beliefs
5. Recognize that some cultural groups have definitions of health and illness as well as practices, that attempt to promote health and cure illness, which may differ from your own.
6. Be willing to adapt your caregiving in keeping with the client's cultural background.
7. Do not expect all members of one cultural group to behave in exactly the same way.
8. Appreciate that each person's cultural values are ingrained and therefore very difficult to change.
9. Don't make assumptions – it's OK to ask questions on cultural issues.

DZepp 3/01

CULTURAL ASSESSMENT

A thorough cultural assessment can take many hours, but we rarely have that luxury. It is believed that, at a minimum, the following list may provide guidance in the cultural assessment of any patient (Lipson & Meleis, 1985).

* Where was the patient born? If an immigrant, how long has the patient lived in this country?

* What is the patient's ethnic affiliation and how strong is the patient's ethnic identity?

* Who are the patient's major support people: family members, friends? Does the patient live in an ethnic community?

* What are the primary and secondary languages, speaking, and reading ability?

* How would you characterize the nonverbal communication style?

* What is the patient's religion, its importance in daily life, and current practices?

* What are the patient's food preferences and prohibitions?

* What is the patient's economic situation, and is the income adequate to meet the need of the patient and family?

* What are the health and illness beliefs and practices?

* What are the customs and beliefs around such transitions as birth, illness, and death?

CULTURAL DIFFERENCES AND SIMILARITIES RELATING TO PAIN, TREATMENT AND DEATH

ETHNIC GROUPS	BEHAVIOR RE: SYMPTOMS	TREATMENTS PREFERRED	SUPPORT SYSTEM	BELIEF RE: DEATH	BEHAVIOR RE: DEATH
Native American	May/may not be expressive	Holistic Purification Medicine man, helps w/journey – not w/cure	Family Shaman Tribal Group	Part of the cycle Return to ancestors Two souls Two choices	Some wail, some quiet Use bells Mourning restraints Ceremonies
Anglo American	From vocal to stoic Some demanding	West. Med. to Alternative & Holistic	Nuclear Family + Friends	Afterlife; judgement, then heaven/hell	Controlled Taboo subject
African American	Emotional Need very clear instructions	Prayer Folk Medicine Magic, Pica Miracle cures	Extended Family Friends Church	Protestants Believe in God's ability to heal	Very emotional!
Hispanic Latino	What will be... Don't talk much about illness, death or dying Need very clear instructions	Curanderos used first Want priest at deathbed Miracle cures Herbs, Cupping	Strong Patriarchal Family Church	Heaven/hell Believe in contact w/dead 90% Catholic Illness/death – God's will	Very emotional! Fascinated w/death
Asian American (general) **Chinese** **Japanese** **Korean** **Indo-Chinese**	Extremely modest re: the body May refuse meds first, need second request Saving face is vital!	Some believe West. Med. may interfere with their spirit Self-healing highly valued Acupuncture Herbs Coining Cupping Folk Remedies	Family Patriarchal Wife and children expected to provide all care	Part of life Need items for the death journey Taoist Buddhist Shinto Ancestor worship Reincarnation Nirvana	Need member of the family present Want to keep body in home as long as possible Women beat breasts: Men jump, cry w/o tears and chant
S. Asian **Indian** **Pakistani**	Don't discuss personal things w/others easily			Hindu Islam Animist	
Filipino	Emotional Accepting	Folk Medicine & West. Med.	Extended Family	90% Catholic	Detailed rituals Very emotional!
Jewish	Emotional Demanding Anxious	Attention Sympathy Good medicine	Family	Many do not believe in heaven/hell	
Arab Mid. Eastern	Women emotional Men demanding and emotional; look down on women medical personnel		Extended Family Islam	Transition See God Resurrection Judgment Paradise/Hell	Express grief openly; stay w/ deceased until transported
Italian	Emotional; appropriate		Extended Family	Catholic Atheist/Agnostic	

K.J. Clayton

Spiritual
Aspects

SPIRITUAL ASPECTS

OVERVIEW

> "We are not human beings on a spiritual journey…
> rather we are spiritual beings on a human journey."
>
> *~ Stephen R. Covey, PhD*

Spiritual care recognizes the need to acknowledge that the search for meaning defines the life ending process for many. Spiritual care *listens* to the heart and soul of another and seeks to *walk* with another on the path that will fulfill their *yearning for meaning*. Most of us, would refer to that *search for meaning* as a search for God in our lives. Remember, we all have a spiritual search, but we all don't choose religion to express that search.

LEARNING OBJECTIVES

By the end of this session, participants will be able to:

1. Discuss spirituality and its place in all our lives.

2. Learn how to companion hospice patients and family members in their own spiritual journey.

3. Learn some ways to invite conversation about the patient's spiritual life by being an active listener.

4. Learn some guidelines and boundaries for caring for the spiritual needs of hospice patients.

Spiritual Care
Spirituality and Core Life Issues
by Rev. Peter Steinke

1. **Mystery ... That Which Is Not Understood or Explained**
   How often have you been asked, "But Why?"
   Sometimes the best thing to do is learn to **accept mysteries.**

2. **Suffering ...** Everyone will suffer in this life. The only way not to suffer is to be in a coma from the moment of your birth until the moment of your death. But it is **how we cope with suffering** that reflects our spiritual journey.

   For some it may be understood as punishment for a past wrong or hurt. This is reflected in cultural or religious traditions. What were you taught about suffering as a child?

   Best thing to do is to be with the patient and listen with all you've got to their own struggling with the meaning of their suffering.

3. **Forgiveness ...** Is a deep need and hunger of the human experience.

   There are five things that can be accomplished for a loved one when they approach dying:

   1. To ask for their forgiveness of wrongs you have done to them.
   2. To give forgiveness of wrongs by the dying loved one.
   3. To say "Thank You" and express what their life meant to you.
      (read the poem, *The Dash*, by Linda Ellis)
   4. To say in anyway you can "I Love You."
   5. To say in anyway you can "Good Bye."

4. **Hope ...** for the dying. Hope may be that someone estranged from the family will come home and be reconciled. Forgiven.

5. **Love ...** for the dying; unconditional love is the real need. But conditional love is what we most often encounter in this life. Love can also be what you see at work in the homes you visit when caregivers are very attentive and caring.

6. **Prayer ...** a deep human instinct. It represents our longing for communication with God, or a Higher Power, or nature.

   Prayer is a part of many rituals and religious traditions.
   Prayer may be individual or communal.
   Speaking, listening, waiting, silence ... all elements of prayer.
   May be directed or non-directed. Non directed prayer appears to be the most effective. Non-directed is no specific outcome prayed for, such as:

   Gracious Lord God, we pray that your Love and Grace would surround Jim today and continue to support him in his life struggles. Into your hands we commit his life. Amen.

   Many styles of praying; what you are comfortable with and **only if, the patient says okay.**

Learning Some Ways to Initiate Conversation About Spiritual Matters

1. Remember that all persons are spiritual beings who express their spirituality in a variety of ways, both verbally and non-verbally.

2. Discovering spiritual concerns is part of the foundation for relationship development with you.

3. Seek always to be an intentional nurturing presence. Do not seek to fix, have an answer, or solution but be with the other person... *companion.*

4. Be aware of your own spiritual needs and tend to them. As you are strengthened, you can strengthen others.

5. Focus entirely on the patient.

6. Some verbal encouragements to spiritual care conversation:

   "You said you had been doing a lot of thinking. Is there anything you would like to share or talk about?"

   "What are your thoughts that you seem to think about most?"

   "You mentioned you didn't know why this was happening to you. Sometimes things are hard or complicated to understand, aren't they?"

   "What seems to give you the most difficulty in understanding or thinking about?"

7. Be aware of the person's family relationships and what seems to be happening in the family.

8. Try to discover what is sacred for this person. What is nurturing for the for the spiritual life of the patient ... Some music, books, objects, foods, rituals, prayer...

   You can share your own sense of the sacred if the patient asks you.

9. It's okay to be silent.

Guidelines and Boundaries for Volunteers: Caring for Spiritual Care

1. Intentional listening - listen without judgment! Focus on the patient alone!

2. Allow the patient to review his/her spiritual story.

3. Allow yourself to reflect back to the patient what you are hearing.

4. Always be aware of your own spiritual journey.

5. Allow yourself the opportunity to express your spiritual journey only when invited by the patient.

6. Resist the urge to give easy answers. (Are there any?)

7. Be tolerant of a person's faith and belief system, especially if it is different than your own. Attempt to understand how that faith system has affected the patient's life - healthy or dysfunctional.

8. Don't get into a theological or doctrinal argument.

9. Put the patient and family in touch with a hospice chaplain or another spiritual advisor of their choice. Encourage contact with their church home minister if they have one.

10. Appreciate always the holistic care provided in hospice.

The Dash

by Linda Ellis

I read of a man who stood to speak
At the funeral of a friend.
He referred to the dates on his tombstone
From the beginning to the end.

He noted that first came the date of his birth
And spoke of the following date with tears,
But he said what mattered most of all
Was the dash between those years.

For that dash represents all the time
That he spent alive on earth
And now only those who loved him
Know what that little line is worth.

For it matters not, how much we own,
The cars, the house, the cash,
What matters is how we live and love
And how we spend our dash.

So think about this long and hard;
Are there things you'd like to change?
For you never know how much time is left
That can still be rearranged.

If we could just slow down enough
To consider what's true and real
And always try to understand
The way other people feel.

And be less quick to anger
And show appreciation more
And love the people in our lives
Like we've never loved before.

If we treat each other with respect
And more often wear a smile,
Remembering that this special dash
Might only last a little while.

So when your eulogy is being read
With your life's actions to rehash
Would you be proud of the things they say
About how you spent your dash?

SPIRITUAL ASPECTS FOR THE DYING

SPIRITUALITY: that part of ourselves that yearns and searches for the One who is the ultimate source of meaning, strength, and comfort - to most of us that is God.

Life's crises and passages often bring out that more intimate search for God. Persons will turn to God at the time of birth and early childhood (baptism, education) or at the time of a significant passage, like marriage. They will also turn to God during illness and death.

We are always on a spiritual journey, yearning and searching for God. At times, our journey demands special attention - like when we are dying. An individual's dying may also trigger spiritual needs for the family and friends.

Hospice has recognized that when pain and symptoms for a dying patient are difficult to control it may be because spiritual issues are unresolved.

Hospice recognizes the need for the "spiritual" along with addressing their physical, mental, emotional, and social needs. We include the patient's own church or provide non-denominational chaplains for addressing those **BIG** questions.

Spiritual cues that may be a door-opener for discussion can include:
"Why is this happening to me?"
"What happens to me after I die?"
"Would you pray with me?"

Mention of forgiveness, regrets, fear of retribution after death, etc. can also be taken as a need for the patient or family to discuss spiritual issues.

Inviting someone to talk about spiritual issues; if you know they have a faith background you can ask the following:
"Your faith must be important to you now."
"I imagine you've thought a lot about God in all this."
"I know you're having a tough time. I guess you might
be wondering where God is in all this."

Then listen. Don't preach, teach, or discuss your personal life or belief about God unless invited to do so. Listen and reflect (repeat what they said) their feelings. You can also say "would you like to say more about that?"

Note any spiritual concerns that may indicate a need for a visit by the pastor or minister. Be sure to get patient/family permission before contacting clergy.

When dying patients have their spiritual needs tended to, they generally have a more peaceful death.

SPIRITUAL TRANSCENDENCE: The Ultimate Goal for a dying patient. Spiritual needs have been met. Patient has ***transcended*** the cares of this world and looks forward to the next. This may happen months before death or with God's grace as late as the last breath.

Transcendence depends on:

- Patient has looked "within themselves" throughout life; know who they are and their life has meaning and purpose. Life review is very important!
- They "trust" in the dying process - they are not alone and kept informed.
- God does not want us to suffer unnecessarily! Pain and symptom medications are appropriate and foster an easier transition through the dying process.
- The caregiver is crucial to healing the spirit of a dying patient. There must be a "letting go" for both. The caregiver needs to assure the patient that they will be okay after death.

Debbie Zepp, Carroll Hospice

Role of Hospice Volunteers in Providing Spiritual Care

1. Be aware of your own spirituality, whether from a religious or non-religious orientation.

2. Be open to spiritual conversations, if you are comfortable. You may have just the right opportunity to help the patient with growth, healing, and a peaceful death.

3. Be prepared for patients with little *religious* involvement to express *spiritual* needs during times of crisis.

4. Be aware of imposing your own spiritual values on the patient or family.

5. Support the spirituality of the patient, even if his/her expressions are different from yours.

6. Be open to sharing your own beliefs, but only if you are asked.

7. Know when to refer a spiritual concern to the Hospice chaplain or family pastor.

Spiritual Companionship is **not** evangelism, therapy, preaching, or dispensing answers to questions of faith. It is simply being with a patient as, in the face of death, they may need to seek and encounter the holy. This work is tremendously significant. With a patient's spiritual needs tended to, the stage is set for a more peaceful death.

A Spiritual Companion:

- Listens more than she talks
- Is aware of her own spirituality
- Meets the patient where he is in his spiritual story
- Respects the patient's thoughts and feelings
- Expresses her own religious/spiritual thoughts only when asked
- Does not judge the patient's faith/belief system, but tries to appreciate how his spirituality has (or has not) served him well
- Resists the urge to offer easy answers
- Is not drawn into theological or doctrinal arguments
- Appreciates the holistic approach of Hospice care

Carroll Hospice attempts to care for the whole person, including physical, relational, and spiritual needs. Our chaplains have prepared the following list of helpful scriptures. If you wish to speak to one of our chaplains, please call the Hospice office.

Helpful Scripture Passages

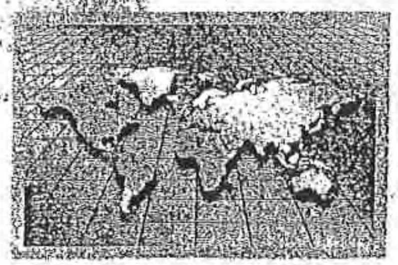
From the Hebrew Scriptures:

Exodus 14	God's deliverance
Isaiah 40:1-11	God's presence and comfort
Isaiah 43:25	God's forgiveness
Isaiah 55	A hymn of joy
Ezekiel 34:11-16	Shepherd of Israel
Psalm 23	The Lord is my shepherd
Psalm 43	God as refuge
Psalm 91	My God in Whom I Trust
Psalm 121	I lift my eyes to the hills
Psalm 143	Prayer for deliverance
Psalm 146	Praise the Lord, O my soul

From the New Testament:

Matthew 5:1-12	The Beatitudes
Matthew 11:25-30	Come to me all who labor
Matthew 28	Jesus' resurrection
John 10	Jesus as the good shepherd
John 11	The raising of Lazarus
John 14	Words to troubled disciples
1 Corinthians 15	The nature of resurrection
2 Timothy 4:6-8, 17-18	I have fought the good fight

CULTURAL PERSPECTIVES IN HEALTHCARE



Culture and the End of Life: A Review of Major World Religions

Charles Kemp, CRNH, FNP-C; Sonal Bhungalia, BSN, RN

This is the last in the series of articles on cultures and end-of-life care. I enjoyed writing and editing the series. In particular I enjoyed writing for you—the hospice and palliative care nurses and others who work at the edge of life and death. It has been an honor.

It seems fitting to end the series with an article on faiths and end-of-life care. Often, faith and culture are intertwined to the extent that it is impossible to tell where one ends and the other begins. In some cases, faith clearly has a far greater impact than culture on how a person and family go through the myriad experiences during the end of life. In other cases, though a person professes a particular faith, it becomes clear that faith has little effect on the experiences. In most cases, however, the approach of death means reflection on faith and ultimate reality; and religion is our common way of understanding the enormity of life and death. —CK

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The same caution that applies to approaching cultural issues also applies to faiths and religion: in writing about these matters we must deal in generalities, but the blind application of these generalities to individuals must be avoided.

This article addresses only the major world religions: Hinduism, Buddhism, Judaism, Christianity, and Islam. They are discussed in approximate order of age, with the oldest coming first and the newest last.

❖ HINDUISM

Hinduism dates back to about the time that Moses received the Ten Commandments, around 1000 to 1500 BC.[1,2] The major Hindu scriptures are the *Vedas*, the *Upanishads*, and the *Bhagavad-Gita* (often referred to as the Gita). The most recent Hindu scripture is the Bhagavad-Gita, which was written somewhere around 800 to 300 BC. Like the Bible, the early Hindu scriptures are a collection of writings by seers or prophets, whereas the Bhagavad-Gita is a dialogue between Lord Krishna and Prince Arjuna.

The goal of Hinduism is freedom (of the soul or *atman*) from endless reincarnation and the suffering inherent in existence. In popular usage, reincarnation and transmigration (rebirth) of the soul are viewed similarly. The endless reincarnations are the result of *karma*, the actions of the individual in this present life and also the accumulation of actions from past lives.

> Free us from sins committed by our fathers; from those through which we ourselves offended (from a hymn to Varuna in the Rigveda)

The caste system is an integral part of Hinduism. Caste divides society into four social classes, with the highest class being the priest class, or the Brahmans and the lowest class being the laborer class, or Sudras. One inherits caste at birth, based on one's karma (see below). Aspects of Hinduism that commonly affect health decisions and communications between patient, family, and provider include:

- Karma is a law of behavior and consequences in which actions in past live(s) affects the circumstances in which one is born and lives in this life. Thus a patient may feel that his or her illness is caused by karma, even though there may be complete understanding of biological causes of illness.
- Belief in one God (Brahman the Creator or ultimate reality); or multiple gods such as Brahman, Shiva, Vishnu, Krishna, and others; or in no gods; or belief in all the preceding with a focus on a particular deity or deities. How can this be, the Western mind may ask? "Atman is Brahman, Brahman is Atman. You yourself are the ultimate reality, but you are not what you seem."[3(p218)] This faith is understood through the experience of enlightenment, and not through linear logic.
- Meditation and prayer are used by many Hindus. Some meditate silently, while others chant "om"and other prayers aloud.

❖ END-OF-LIFE PRACTICES

Many Hindu patients prefer to die at home; and some will go back to India, especially to the sacred city of Varanasi, to die. Consistent with the Western idea of resolving unfinished business, a Hindu who is elderly or terminally ill may put significant effort into resolving relationships and other such personal matters. Dying full of anger or fear leads to a lower level of rebirth than dying full of love and acceptance. It is important to understand that a devout Hindu believes that she or he has already been born and died many times in the past, and this contributes to increased acceptance.

The idea that suffering is inevitable and the result of karma may result in difficulty with reporting symptoms and with symptom control. Many will seek a conscious dying process and death, hence choose discomfort over clouded sensorium. Difficulties between hospice staff and family or the patient may arise when therapeutic measures are refused, especially when it seems that the patient may want or need the therapy, but the family influences her or him to refuse.

A person near death should be placed with her or his head facing east and a lamp placed near the head. Family members are likely to be present in large numbers as death nears. Chanting and prayer, incense, and various rituals are part of the process. These may include application of sacred ash or paste to the person's forehead, placing a few drops of milk or water from the sacred Ganges River (Ganga Ma) in the dying person's mouth. Ideally, the person who is dying will chant her or his mantra (a personal sacred phrase) as death occurs. If this is not possible, a family member may softly chant the mantra in the person's right ear. If there is not a chosen mantra, then *Aum Namo Narayana* or *Aum Nama Sivaya* may be used.

The moment of death is seen by some as similar to falling asleep, with the difference being that in sleep the silver cord that connects the body to the soul stays intact in sleep, but breaks in death.

After death, the family should be the only ones to touch the body, hence healthcare staff should touch the body as little as possible. Ideally, a family member should clean the body and this person should be of the same sex as the deceased. After being cleaned, a cloth is tied under the chin and over the top of the head, the thumbs and great toes tied together, and the body is wrapped in a red cloth and placed with the head facing south. Embalming and organ donation are prohibited.

When a person dies in a hospital, the family may want the death certificate signed as soon as possible and then transport the body home rather than to a funeral home. At the home, religious pictures are turned to the wall and mirrors may also be covered. The ceremony at the home includes prayer, incense, chanting, and singing sacred songs.

The preference is for cremation and, ideally, the ashes are spread over the holy river, Ganga Ma. The men and boys of the family may shave their hair as a symbol of mourning for the dead. The mourning family may wear all white and wish to have a Brahman at the funeral to perform a prayer and blessing.

❖ JUDAISM

Judaism dates back to the Prophet Abraham around 1500 to 1000 BC. The central belief in Judaism is in the one God. *"Hear O Israel: the LORD our God is one LORD"* (the *Shema*, from Deuteronomy 6). The practice of this belief includes following the Law, living according to the ethics derived from the Law, following ritual, and supporting "the people, Israel." The sacred books of Judaism are:

- The *Torah* (Genesis-Deuteronomy)
- *TaNaK* or the Hebrew Bible (Torah; Neviim or prophets such as Joshua, Samuel, Isaiah; and K'tuvim or sacred writings such as those of King David, Jeremiah and Eichah)
- *Talmud*, consisting of a legal code written in Hebrew called the Mishnah and an Aramaic commentary on the Mishnah called the Gemara

From the Torah, the pogroms in Europe and Russia, and from the Holocaust, have come Zionism and the modern state of Israel. *"The LORD said to Abram, `Go from your country and your kindred and your father's house to the land that I will show you'"* (Genesis 12:1). There are three main branches or movements[4] in Judaism:

- Orthodox Jews (7% of American Jews) practice strict observance of halakhah or Jewish Law, and believe that God (written as G-d to avoid defacing the name of the Lord) gave Moses the entire Torah as well as the oral tradition of the Torah. Within the Orthodox movement are modern Orthodox who tend to blend into society as a whole and the Chasidim (sometimes erroneously termed "ultra-Orthodox"), who live separately and dress distinctively.
- Conservative Judaism (38% of American Jews) views the Torah and other sacred writings as coming from God, but transmitted by humans and thus possessing a human component. Conservative Jews follow halakhah, but with the belief that the Law can remain true to Judaism's values while changing in accordance with the dominant culture.
- Reform Jews (42% of American Jews) are the most liberal and [redacted] believe that the Torah was written by God. While not following the strict interpretation of the Law, Reform Jews hold to the values and ethics of the faith.

There are other movements, such as Reconstructionism, but these have significantly fewer followers than those discussed above. Note also that for many, being Jewish is not only following having the faith; but also being part of the ancient lineage of "the people, Israel."

The Sabbath or *Shabbat* begins on Friday 18 minutes before sunset and ends on Saturday, about 40 minutes after sunset, when three stars can be seen. Shabbat should not be confused with the Christian Sabbath. Shabbat is primarily a time of rest and spiritual enrichment; and is comprised of two main components:

- To remember the significance of Shabbat as a commemoration of creation and as a commemoration of Jewish freedom from slavery in Egypt.
- To observe Shabbat by following ritual and prohibitions. Note that what is prohibited on Shabbat is permitted to preserve life. The original prohibitions were based on work necessary to build the sanctuary and the modern prohibitions are derived from these, eg, driving a car is prohibited—at least among Orthodox Jews.

There are a number of religious holidays, celebrated to various extents according to movement and personal inclination. These include Yom Kippur (the Day of Atonement), Pesachr (Passover), Rosh Hashana (the Jewish New Year), and other celebrations. Readers are referred to Judaism 101 (*http://www.jewfaq.org/*) for in-depth and interesting discussions on religious holidays and other facets of Judaism.

❖ END-OF-LIFE PRACTICES

Jewish patients do not seem to have a strong preference for place of death. The issue more critical than place may be the availability of spiritual support and freedom to practice ritual. Spiritual care is best provided by a rabbi, but a person of any faith may appropriately read to the patient from the Torah, Psalms, or another Jewish holy book. Family involvement is likely to be considerable, especially among Orthodox Jews. Discussion of prognosis and related matters are a matter of personal preference.

Withholding or withdrawing treatment in terminal illness is a matter of personal preference. Treatment with double-effect (palliation of symptoms at the cost of life) is not prohibited, but euthanasia and assisted suicide are clearly forbidden. Autopsy is acceptable if required by law, but no parts should be removed. Organ transplants are permitted with consultation from a rabbi.[5,6]

Deathbed confession and repentance are traditional, as are blessings and ethical instruction to loved ones. There is not, however, a corollary to last rites.

After death, the body's eyes should be closed, preferably by a relative, but there are no prohibition against non-Jewish persons touching the body. The body should then be straightened and covered. Ideally, a family member stays with the body until burial. Cremation, embalming, and what funeral homes often term "restoration" (applying makeup and the like) of the body are prohibited, as is public viewing and the use of an ornate coffin. Most synagogues have a *cheura kaddisha* or burial society that prepares the body according to Jewish practice. Burial should occur within 24 hours of death, except that burial should not take place on the Sabbath.

The *Kaddish* is an ancient Jewish prayer associated with the end-of-life (see below, and compare to the Lord's Prayer in the Christian New Testament, Matthew 6:9-13). Observant Jews only recite the Kaddish in the presence of 10 males; and even liberal Jews say the ayer in Aramaic.

Mourner's Kaddish
May His great Name grow exalted and sanctified
(Congregation: Amen)
in the world that He created as He willed.
May He give reign to His kingship in your lifetimes and in your days, and in the lifetimes of the entire Family of Israel, swiftly and soon.
Now respond: Amen.
(Congregation: Amen. May His great Name be blessed forever and ever.)
May His great Name be blessed forever and ever.
Blessed, praised, glorified, exalted, extolled, mighty, upraised, and lauded be the Name of the Holy One, Blessed is He
(Congregation: Blessed is He)
beyond any blessing and song,
praise and consolation that are uttered in the world.
Now respond: Amen.
(Congregation: Amen).
May there be abundant peace from Heaven, and life upon us and upon all Israel.
Now respond: Amen.
(Congregation: Amen).
He Who makes peace in His heights, may He make peace, upon us and upon all Israel.
Now respond: Amen.
(Congregation: Amen).

There is a prescribed period and ritual of mourning. The first period is called shivah and is divided into an initial period between death and burial in which the mourner is exempt from all positive religious obligations. The mourner is said to be between life and death and is called a *goses*. The 7 days of mourning between burial and the end of the *shivah* has special stringencies such as sitting only on a low bench or on the floor. During that period it is improper for friends to exchange greetings with the mourner. One simply comes into the mourner's presence; except that it is permitted to use this phrase in Hebrew: "May you be comforted among the mourners of Zion and Jerusalem."

The 30 days after shivah (shloshim) have fewer restrictions than the first 7. For example, mourners can sit on regular chairs and exchange greetings. But until the end of the mourning period, mourners are prohibited from attending parties or light occasions. The Kaddish Yatom (orphan's Kaddish) is said regularly until the conclusion of the mourning period.

After 1 year, there is for some a modern convention of a ceremony in which the name of the deceased is placed in a memorial room in the synagogue. Another modern convention is the practice of unveiling a grave stone on the first anniversary of death and saying Kaddish with friends and family at the graveside.

❖ BUDDHISM

Buddhism began in the 6th century BC, both as a reform of Hinduism and as a response to the suffering inherent in the human condition, epitomized by illness, aging, and death. The founder of Buddhism was Gautama Siddharta (also spelled Siddhartha) the Buddha (in Sanskrit "The Awakened" or "The Enlightened").

There are two main branches in Buddhism: *Theravada Buddhism*, or the "lesser vehicle," which is practiced most often by people from Cambodia, Laos, Thailand, Burma, and Sri Lanka; and *Mahayana Buddhism*, or the "greater vehicle," which is practiced most often by people from Vietnam, China, and Japan. There also are other aspects of Mahayana Buddhism, such as the Zen Buddhism of Japan and the Lamaism of Tibet. In the Western world, there are differences based on nationality or ethnicity, so that in a particular location, there may be one or more each of a Laotian temple, a Cambodian temple, a Chinese temple, and so on.

In Theravada Buddhism, *Nirvana*, or emancipation from rebirth, is achievable only through complete renunciation (nonattachment) and through living as a monk. The Buddha is "revered, not as a god but as one who has shown the way."[7(p16)] In practice, among the laity and many monks, the reverence shown to the Buddha and images of the Buddha is like that shown to a god. In some branches of Mahayana Buddhism, *Nirvana* is possible for non-monks, and among laypersons there appears to be a greater belief in (often multiple) deities, in heaven, and in hell. More sophisticated monks are apt to view these as states of mind.

The earliest Buddhist scripture is the Theravada *Tipitika* or Three Baskets. Originally written in Pali, the liturgical language of Theravada Buddhism, the Tipitika includes rules of the order, discourses, and teachings on metaphysics. The essence of Buddhism is found in the Four Noble Truths, the realization of which resulted in Gautama becoming the Buddha. The Four Noble Truths are:

- All sentient beings suffer. Birth, illness, death, and other separations are inescapably part of life.
- The cause of suffering is desire (*tanha*). Desire is manifested by attachment to life, to security, to others—most specifically the desire "to be."[5]
- The way to end suffering is to cease to desire.
- The way to cease to desire is to follow the Eightfold Path: (1) right belief, (2) right intent, (3) right speech, (4) right conduct or action, (5) right endeavor or livelihood, (6) right effort, (7) right mindfulness, and (8) right meditation.

Following the Eightfold Path leads to cessation of desire and to Nirvana.

Although Buddhist scripture has nothing to say about magic, belief in magic is common among some Buddhists, especially people from the Theravada countries of Thailand, Cambodia, and Laos, and also among Tibetans. Magico-religious practices are well integrated into Buddhism, and include use of amulets, spells, and the presence and power of spirits. It is not uncommon for persons from these countries to return home for the sole purpose of obtaining a talisman or blessing from a particular monk in much the same way as some Christians might journey to Lourdes or other holy place.

✣ END-OF-LIFE PRACTICES

The Buddha did not give specific answers to the questions of dying and death—except that they are inevitable. On the question of immortality, the Buddha gave the "fourfold denial":

> A saint is after death. A saint is not after death. A saint is and is not after death. A saint neither is nor is not after death.[8]

Buddhist scholars thus see four possibilities regarding life after death; the less scholarly, ie, the majority of Buddhists, are likely to believe in rebirth according to deeds, ie, karma (written in Pali as kamma).

A key issue in dying for many Buddhist patients and families is to maintain consciousness so that patients can go through the process of dying with equanimity and "wholesome thoughts." Wholesome thoughts include awareness of the transient nature of existence, reflection on past "good efforts," and letting go of life "without clinging and grasping."[9(p396)] A quiet place for dying is preferred to a noisy or busy unit. A monk or lay religious leader may chant or lead chants to help promote a peaceful or insightful state of mind at death. Incense may be burned and amulets, including images of the Buddha, may be placed near the person who is dying.

Organ transplant and autopsy are non-issues for most Buddhists. People other than Buddhists may touch the body, and there is no definitive belief about how the body should be treated (except of course, with respect) and when it should be buried or cremated. The question of burial or cremation is more cultural than religious. Among some Southeast Asians, the family will wash the body and place the hands in a prayerful position. In many cases, if possible, the body should be kept at the home so that ceremonies may be conducted.

White is the color of mourning and some close relatives may shave their heads as a sign of mourning. The temple is also the site of ceremonies, both soon after the death, at 100 days, and at other times, such as when there is enough money for a proper ceremony.

> *Thus shall ye think of all this fleeting world: a star at dawn, a bubble in a stream; a flash of lightning in a summer cloud; A flickering lamp, a phantom, and a dream.* From the Diamond Sutra (of the Buddha)

✣ CHRISTIANITY

Christianity began approximately 2000 years ago with the birth, teachings, miracles, crucifixion, and resurrection of Jesus Christ, the Messiah or son of God. The coming of the Messiah was prophesied in the Old Testament:

> Behold, a young woman (or virgin) shall conceive and bear a son, and shall call his name Imman'u-el. (Isaiah 7:14)

The holy book of Christianity is the Bible, composed of the Old Testament (set forth before the birth of Christ) and the New Testament (written after the birth of Christ).

The divisions of Christianity best known by laypersons in the Western world are Protestant and Catholic. There are also numerous divisions according to variations on the basic beliefs and the great division between those who take the Bible as the literal Word of God and those who take the Bible as the inspired word of God. The earliest division in Christianity was between the Western Church or Church of Rome (Catholic) and the Eastern Church or Orthodox Church in 1054 when Pope Leo IX condemned the Patriarch of Constantinople.

The Nicene Creed summarizes the beliefs of Christianity in a manner acceptable (except as noted) to both the Eastern and Western Churches:

> I believe in one God the Father Almighty, Maker of heaven and earth, and of all things visible and invisible;
>
> And in one Lord Jesus Christ, the only-begotten Son of God, begotten of His Father before all worlds; God of God; Light of Light; Very God of Very God; Begotten, not made; Being of one substance with the Father, by whom all things were made; Who for us men, and for our salvation, came down from heaven; And who was incarnate by the Holy Ghost of the Virgin Mary, and was made man; And was crucified also for us under Pontius Pilate.
>
> He suffered and was buried; And the third day He rose again according to the Scriptures; And ascended into heaven; And sitteth on the right hand of the Father. And He shall come again with glory to judge both the quick and the dead;
>
> And I believe in the Holy Ghost; the Lord and Giver of Life; Who proceedeth from the Father and the Son;[*] Who with the Father and the Son together is worshipped and glorified; Who spake by the prophets. And I believe in one Holy Catholic and Apostolic Church. I acknowledge one Baptism for the remission of sins. And I look for the resurrection of the dead; And the Life of the world to come. Amen. (From the Presbyterian Hymnbook)

Christian sacraments include the following:

Catholic sacraments most associated with the end-of-life are Reconciliation (Confession or Penance), Holy Communion (Eucharist), and Anointing of the Sick (Last Rites). Statues and pictures of Jesus, Mary, and saints are widely used.

Protestant sacraments most associated with the end-of-life are Holy Communion and in some cases, Baptism. Though not a Protestant sacrament as such, confession has a long tradition in all branches of Christianity.

Eastern Church sacraments associated with the end-of-life include Penance, Unction of the sick and prayers for the "separation of soul and body," Confirmation (anointing), and Holy Communion. There also is widespread use of icons of Jesus, Mary (*Maryam*), and the apostles.

❖ END-OF-LIFE PRACTICES

In the largely Judeo-Christian Western world, the variety of practices and approaches to dying and death among Christians defy summary. However, several points may be made. In most cases, spiritual care may be given by lay persons as well as ministers and chaplains. Reading to patients from the Bible or praying with (or for) patients and families is usually appropriate. Among the passages most associated with the end-of-life are:

> I am the resurrection and the life: he who believes in me, though he die, yet shall he live, and whoever lives and believes in me shall never die. (John 11:25-26)
>
> Let not your hearts be troubled; believe in God, believe also in me. In my Father's house are many rooms; if it were not so, would I have told you that I go to prepare a place for you? (John 14:1-2)
>
> My God, my God, why hast Thou forsaken me? Why art Thou so far from helping me, from the words of my groaning... (Psalm 22; also see other Lament Psalms 13, 22, 38, and 51 for people in despair)
>
> The Lord is my shepherd, I shall not want; He makes me lie down in green pastures. He leads me beside still waters; He restores my soul (Psalm 23:1-3)

Withholding or withdrawing treatment at the end-of-life is a matter of personal preference. Treatment with

---

[*] *The Eastern Church holds that the Holy Ghost proceeds only from the Father, not from the Father the Son (the filioque clause).*

double-effect (palliation of symptoms at the cost of life) is not forbidden, but in most cases, euthanasia and assisted suicide are clearly forbidden. Autopsy is acceptable and organ transplants are permitted in most denominations.

Deathbed confession and repentance are traditional, and in Catholicism and Orthodox Church, are according to ritual. Even when not expected (as among Catholics and Orthodox), Holy Communion is a very powerful event for people with terminal illness.

There is no prescribed preparation of the body and funerals vary widely according more to culture and individual preference than religion (except that each denomination has usual practices and passages). Until very recently, expectations of mourning among Christians in the Western world has tended to be minimal, that is a very brief period of mourning followed by rapid recovery and getting on with life. The hospice movement is largely responsible for re-examination of mourning practices in the Western world and for acknowledging that healing may be a long, slow process.

✣ ISLAM

Islam began in the year 610 AD when according Muslim belief, the Angel Gabriel began to reveal the Word of God to the Prophet Muhammad. The word Islam, in Arabic, means surrender, specifically to God; and a Muslim is one who surrenders to God. The foundation and unifying belief or *tawhid* of all Islam is the belief in One God (Allah).

> God! There is no God but Him, the Living, the Ever-existent one (Qur'an, The Imrans 3:1)

Flourishing in Europe, Africa, Asia, and Middle East, Islam is the youngest and fastest growing world religion. The major divisions of Islam are Sunni and Shi'a, and the various schools or sects within the larger divisions. There are also significant divisions between fundamentalists and secularists, but with widespread sympathy for fundamentalists among more secular Muslims.

The scripture of Islam is the *Qur'an*, which is believed to be God's Revelation to the Prophet Muhammad. The Qur'an is divided by chapters or *Surahs*, which are arranged according to revelation. Except for the first Surah, arrangement is from longest to shortest. The Qur'an gives explicit rules or "legislation" for Muslims, with halal describing what is lawful and haram what is unlawful. Examination of the earliest known copies of the Qur'an show significant differences between early and more recent editions; and between history and dogma. Serious scholarship is inhibited by the potential for violence against scholars.[10]

In addition to the Qur'an there is the Tradition or *Hadith*, "the Sayings and Doings of the Prophet Muhammad." The Hadith is the body of traditions upon which much of the life and traditions of the Muslim community is based. The Hadith is a vast work that evolved from texts appearing from 130 to 300 years after Muhammad's death and may, in some respects, modify or contradict the Qur'an.[10,11]

After belief in God there is belief in angels, Satan, spirits (*jinn*), the Day of Reckoning, Heaven and Hell, and in the Prophets and Messengers (including Abraham, Moses, Joseph, and Jesus). Muhammad is considered to be God's (Allah's) final Prophet and Messenger. There are also five "pillars of faith." These are:

- Faith in the one God, explicated by daily recitation of the testimony or shahada: *There is no God but Allah, and Muhammad is His Prophet*
- Daily prayer or *salat* at least five times daily
- Alms-giving or *zahat* (or *zakat*)
- Fasting or *sawm* (sunrise through sundown), principally during Ramadan
- Pilgrimage or *hajj* to Mecca, if possible.

Friday is the most important day of worship. Regular worship takes place in mosques, and in non-Muslim countries major holidays or ceremonies may be held at public places to accommodate large crowds.

✣ END-OF-LIFE PRACTICES

Although the Qur'an seldom speaks directly to issues of sickness or physical health, related issues are addressed. Among these are the importance of cleanliness (especially ritual cleanliness), prayer, modesty, dietary restrictions, and fasting.

- Ritual cleansing is performed at least five times/day as preparation for prayer.
- Prayers (salat) are said at least five times daily, with the person praying facing Mecca (to the East). If a patient is unable to kneel, she or he may turned to face Mecca.
- Modesty is more of an issue for Muslims, generally speaking, than for people of other faiths. Same-sex health providers should be used as much as possible.

- Dietary restrictions include pork and meat from animals killed outside of Muslim custom, and eating from dishes or with utensils that have had contact with proscribed foods (hence the refusal to eat food prepared at the hospital).
- Fasting during daytime in the holy month of Ramadan is required for all adults, except those who are ill. Some Muslims, however, will neither eat nor take medicine during Ramadan—regardless of circumstance.

Among Muslims from the Middle East, quick pain/symptom relief is expected; but the expression of pain, except during labor and delivery, is often private. It is seldom desirable for a non-Muslim to read from the Qur'an as a means of spiritual care; and seldom practical, as the Qur'an is generally read in Arabic. Rituals related to dying include the patient facing Mecca, confession of sins, prayer, and reading or recitation of verses from the Qur'an (especially the 36th surah, Ya Sin) into the ear of the person who is dying by the eldest man present.

> Lo! those who merit Paradise this day are happily
> employed, They and their wives, in pleasant shade, on
> thrones reclining; Theirs the fruit (of their good deeds)
> and theirs (all) that they ask; The word from a Merciful
> Lord (for them) is: Peace! But avaunt ye, O ye guilty,
> this day! (Qur'an, Ya Sin 55-59)

After death, non-Muslims should not touch the body. The family or a designated person from the community is responsible for washing and preparing the body. Most Muslim scholars have the opinion (*fatwa*) that autopsies are not allowed[12] except when required by civil law and that organ donation may be allowed when necessary.[13] The funeral should take place as quickly as possible and the body buried in a Muslim cemetery when available. Mourning is a family and public community process, with men and women mourning separately.

Acknowledgments

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Erratum

In the Panorama section of the July/September issue of *JHPN*, some information about the author of the book review on *Handbook of Religion and Health* was inadvertently left out. The full author affiliation should read: "Terence Cronin, MAR, is a graduate of Yale Divinity School. He has worked in the areas of parish ministry, spirituality and healthcare administration for more than 20 years. For the past 7 years he has worked in hospice care and currently serves as Executive Director of Hospice of Maine."

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Volunteer
Role

LIMITS TO CARE

In working with patients, you may tend to want to help all individuals facing problems of all kinds. However, our agency was established to provide a very specialized service. If you observe needs or issues unrelated to the patient's dying process or the family's coping system, our social worker will be able to assist the family in directing them to the appropriate services offered in Carroll County. It is important that Carroll Hospice work within its own program guidelines to meet our patient/family needs in regard to the dying experience. If you are familiar with services that could help the family, be sure to discuss this with the volunteer coordinator or other hospice staff before taking steps.

ALSO REMEMBER:

- Not everyone wants or will accept help. Patients and families have the freedom to choose what services they wish.
- You are not working as a nurse or nursing assistant (even if you are qualified in your regular career). You may **NOT** administer medication or offer medical advice of any kind.
- Always contact the volunteer coordinator or hospice staff member if you feel a patient needs to be referred or is not appropriate for hospice care.

CONFIDENTIALITY

Carroll Hospice is very diligent about maintaining patient and family confidentiality. Some families are very open about their personal issues while other families take exception to any discussion of personal matters. We must respect the rights of our patients by **NEVER** discussing our hospice cases outside of hospice personnel.

BE AWARE OF PATIENT NEEDS

Despite the hours of training you have undertaken, you may be assigned to patients and families who only want minimal contact with a volunteer. This is discouraging to the assigned volunteer, but it is a part of the hospice philosophy to "meet patients and families where they are" and we cannot interact with them more than they will allow. These patients may only wish a weekly phone call, or a run to the grocery store or just your phone number to have, if needed. We always want a chance to really talk with and get to know our patients and families, but the reality is, we can only give what they are willing to take! Don't be discouraged. Your availability to that family by waiting in the wings is just as important as making daily visits. You'll be there when they need you.

ENDING A CASE

Just as each case is different in the dying process, so too is the way the volunteer ends their association with the family. Long-term cases (4 months or longer) usually generate a stronger connection with the volunteer. This may result in the volunteer themselves, needing to extend contact by visit or phone over a longer period following the patient's death. If the case runs less than 4 months and the volunteer/family attachment is not too strong, it is recommended that at least 2 follow-up calls be made or attendance at the viewing, funeral or memorial service is adequate. Remember that the bereavement program becomes effective at the patient's death and continues for 13 months following the death. This should be comforting to the volunteer, knowing that a hospice representative is still in touch with the family.

Active volunteers may carry several cases throughout the year. Trying to keep up with each family over a long period would be extremely difficult and tiring. The last thing we need is a "burned out" volunteer! Most families are understanding and do not need the volunteer to continue contact following a death. Notify the volunteer coordinator if a family member expresses distress over the volunteer discontinuing contact. Our bereavement staff will be glad to handle the situation.

CARROLL HOSPICE

MONTHLY VOLUNTEER FLOW SHEET

- Record ALL volunteer time on this form and attach caregiver notes if applicable.
- This form must accompany your Volunteer Caregiver Report for Home or Nursing Facility Direct Patient Care.

Name (please print) ______________________________ **Month/Year** ____________

Please enter your activities' minutes and hours in quarter-hour increments as follows:

0-15 minutes = .25 16-30 minutes = .50 31-45 minutes = .75 46-60 minutes = 1 hour

ACTIVITY	DATES						
Example:	14	21	28				
GENERAL SUPPORT	3.75	2.00	.50				
Enter Dates Here →							
DOVE HOUSE INPATIENT VISIT Direct Patient/Family Care/Reception							
HOME OR NURSING FACILITY VISIT rect Patient/Family Care, BV Care, Telephone Support, PCS or Supply Delivery, etc.							
ADMINISTRATIVE SUPPORT Clerical, Indirect Patient Care							
PUBLIC RELATIONS Fundraisers, Health Fairs, Community Activity for Hospice							
MEETINGS Training, Inservices, Education, Supervisor Meetings							
GENERAL SUPPORT Camp TR, Memorial Services, Prayer Shawls, Construction, etc.							
TOTAL <u>TIME</u> SPENT TRAVELING TO & FROM ACTIVITY (ROUND TRIP)							
TOTAL <u>MILES</u> TO & FROM ACTIVITY (ROUND TRIP)							

CARROLL HOSPICE
IN-PATIENT UNIT VOLUNTEER REPORT

CARROLL HOSPICE

Instructions:

Complete this form before the end of your Dove House shift or immediately after visiting patient.

1. All information should be filled in completely – Keep comments objective and concise. This can include time with patient, family, or other visitors while anywhere in the unit (patient room, dining room, family room, etc.)
2. Contact Nurse's station or appropriate Hospice Staff to report any immediate concerns. (e.g. pain issues, imminence of death, emotional crisis, safety issues, etc.)
3. Place the completed form in the provided area in the copy room behind the reception desk.

Volunteer Name:	Patient Name:

Date: ________/________/________ Time In: ____________ Time Out: ____________

PATIENT/FAMILY CONCERNS:

VOLUNTEER COMMENTS:

(If Appropriate)

Hospice Staff Notified: Yes / No Name of Contact: ______________________________

Outcome (If known): ______________________________

____

Volunteer Coordinator signature: ______________________________

CARROLL HOSPICE

CAREGIVER VOLUNTEER REPORT

Instructions:

1. Complete & deliver this form to hospice office monthly or within 3 days of patient death.
2. Volunteer Flow Sheet must accompany Volunteer Report for recording of time and mileage.
3. All information should be filled in completely - Keep comments *objective* and concise.
4. Contact Volunteer Coordinator or appropriate Hospice Staff member to report any immediate concerns. (e.g.: pain issues, imminence of death, emotional crisis, safety issues, etc.)
5. Caregiver Volunteer Report to be used for bereavement contacts made following patient death.

Volunteer Name: **Patient Name:**

Date: ________/________/________ Time: In________ Out________

Type of Contact: Visit_____ Phone______ Errands______ Emergency Referral_____ Respite_____ Other_____ Bereavement_____

PATIENT/FAMILY CONCERNS:

VOLUNTEER COMMENTS:

Hospice Staff Notified _____Date___/___/___Reason for Contact ____________________ Name of Contact ______________________
(If appropriate)

________/________/________ Time: In________ Out________

Type of Contact: Visit______ Phone______ Errands______ Emergency Referral_____ Respite_____ Other_____ Bereavement_____

PATIENT/FAMILY CONCERNS:

VOLUNTEER COMMENTS:

Hospice Staff Notified _____Date___/___/___Reason for Contact ____________________ Name of Contact ______________________
(If appropriate)

Date: ________/________/________ Time: In________ Out________

Type of Contact: Visit______ Phone______ Errands______ Emergency Referral_____ Respite_____ Other_____ Bereavement_____

PATIENT/FAMILY CONCERNS:

VOLUNTEER COMMENTS:

Hospice Staff Notified ______Date___/___/___Reason for Contact ____________________ Name of Contact ______________________
(If appropriate)

Sample - Do not use pencil.

CARROLL HOSPICE
CAREGIVER VOLUNTEER REPORT

structions:

1. Complete & deliver this form to hospice office monthly or within 3 days of patient death.
   'olunteer Flow Sheet must accompany Volunteer Report for recording of time and mileage.
   ll information should be filled in completely - Keep comments *objective* and concise.
4. Contact Volunteer Coordinator or appropriate Hospice Staff member to report any immediate concerns. (e.g.: pain issues, imminence of death, emotional crisis, safety issues, etc.)
5. Pink Caregiver Volunteer Report to be used for bereavement contacts made following patient death.

'olunteer Name: Jane Doe **Patient Name:** Sally Sue

ate: 2 / 6 / 06 Time: In 9:15 Out 10:15 A

pe of Contact: Visit ✓ Phone____ Errands____ Emergency Referral____ Respite____ Other____ Bereavement____

ATIENT/FAMILY CONCERNS: Pt complaint of arm pain and cough. Wife not getting much sleep.

OLUNTEER COMMENTS:

Wife expressed exhaustion and was tearful. Appreciative of my listening so she could talk freely. Pt. slept thru most of visit. Other family members supportive. Hospice RN to vst tommorrow.

ospice Staff Notified ✓ Date 2/6/06 Reason for Contact pt arm pain & cough Name of Contact Vicki Nurse
appropriate)

---

ate: 2 / 9 / 06 Time: In____ Out____

pe of Contact: Visit____ Phone ✓ Errands____ Emergency Referral____ Respite____ Other____ Bereavement____

ATIENT/FAMILY CONCERNS:

None reported

OLUNTEER COMMENTS:

Called to check on wife and patient. Pt stopped coughing. RN addressed arm pain with medication. Next vst set for 2/12/06

ospice Staff Notified ____ Date__/__/__ Reason for Contact ________ Name of Contact ________
appropriate)

---

ate: ____/____/____ Time: In____ Out____

pe of Contact: Visit____ Phone____ Errands____ Emergency Referral____ Respite____ Other____ Bereavement____

ATIENT/FAMILY CONCERNS:

OLUNTEER COMMENTS:

ospice Staff Notified ____ Date__/__/__ Reason for Contact ________ Name of Contact ________
appropriate)

CARROLL
HOSPICE

Transaction Summary

Volunteers should never use their own money for purchases. Please have client or family provide some form of payment prior to transaction.

Please have client or family member sign upon delivery of items.

Transaction Date:	Volunteer:
Patient Name:	
Items Purchased:	
Payment Method:	Cash Amount Prior to Errand (if any):
Total Cost of Transaction:	Change Returned to Patient:

Patient/Caregiver Signature: ______________________________

Volunteer Signature: ______________________________

GUIDELINES FOR PATIENT/FAMILY VOLUNTEERS

THE FIRST VISIT

Your first visit to a patient/family can be a challenge. Will they like me? Will I be able to help? What will I do? These questions are natural, but trust yourself. How you interact will be based on your life experiences, your common sense, your intuitions and the knowledge you gained in volunteer training.

Maintain an attitude of openness and receptivity to the needs of your patient and family. They will let you know what they need. You, in turn, need to let them know what you can offer. The relationship will unfold step by step in a very natural way.

BE YOURSELF

Relate to the patient with the same personality displayed in any other situation. People who are ill appreciate being treated naturally, and in this way are reassured that their illness has not set them apart any more than in the obvious ways. Relate to the patient, not the illness.

The volunteer role is that of friend and supporter, not expert or authority. You are not expected to know all the answers. Refer medical questions to the hospice nurse. Clear communication with the family: hospice staff will let you know the initial needs and expectations of the patient/family. Be aware that these may change as the patient's condition changes.

LISTENING

Always remember, your function as a volunteer is to meet the needs of your patient/family, not your own. Their situation is always the focus of your visit. In most instances this means listening more than talking. Avoid the natural tendency to swap medical stories or confide in them. Remember, you're establishing an objective relationship, not a subjective one.

Your support might involve listening to the same stories over and over again; stories that, for whatever reason, satisfy a need of the patient or the family member in the telling. It may mean listening non-judgmentally to outbursts of anger, frustration, and resentment. If you are the target for some of these negative feelings, don't take it personally. Such outbursts can release tension and might lead to the expression of other concerns.

Take a book, crossword puzzles or needlework to keep you occupied if a patient is sleeping. By your having something to do, the patient feels less pressured to entertain you. Sometimes not talking, but sitting with a patient and caring by simply being there is the greatest gift of all.

SHARING INFORMATION WITH OTHER TEAM MEMBERS

As a volunteer, you will often become a trusted confidant. It is in the best interests of the patient and family that all pertinent information be shared with the team. At no time should a volunteer promise not to tell anyone any piece of information shared by a patient or family member.

The patient and family will have been assured confidentiality by hospice. They will also understand that hospice care is provided by a team of professionals who must communicate with each other. Use your common sense when deciding what information other team members need to know.

DEPENDIBILIY

To people in crisis whose lives are subject to so much unpredictability it is essential to know that they can count on someone or something. The lives of seriously ill persons can have little variety and few distractions. Therefore, each outside contact can take on heightened significance. What may be a minor part of your week could be the single event the patient has been eagerly awaiting for days. It may also be the only opportunity the primary caregiver has to have some private time away from the responsibilities of patient care. Never offer more than you know you can deliver. If an emergency requires you to change plans you have made with the patient and family, be considerate and let them know.

PHYSICAL CONTACT

Some people like to touch and be touched; others don't. You need to be flexible with this issue and sensitive to the needs of the patient and family.

Patients and family members usually welcome appropriate physical gestures as a means of communicating caring. Hand holding, a hand on the arm or across the shoulders tells them I'm here. I care. Such contact is a way to connect without words. Conversation might be tiring for a patient or family member.

This dimension of the relationship will, of course, evolve naturally with the passage of time and the intensity of events. Be open. Do what feels right based on what your patient and family indicate they need. Some people may not need such support.

MEET PEOPLE WHERE THEY ARE

Hospice always respects the needs and decisions of each patient and family. Supporting and accepting their values, choices and life patterns is essential. It is never appropriate to give unsolicited advice, no matter how much you disagree with the family's way of dealing with their situation.

Patterns of interaction between family members, no matter how they seem to you, have been formed over years of association and are rooted in a history of which you are not a part. Your responsibility is to work as helpfully and harmoniously as possible within the given structure, not to try to change it. Be accepting and non-judgmental at all times of the feelings, words, actions and decisions the patient and family share with you.

LITTLE THINGS MEAN A LOT

Your personal grooming and manner of dress can affect a patient's mood. Color and attractiveness can help lift the spirit. Don't wear perfume or aftershave lotion. A patient's sense of smell can be extremely sensitive; strong fragrances can be nauseating.

Positive attitude and pleasant expression mean a lot. This does not mean phony cheerfulness or overly bright chattiness, but merely a clear message of caring and attention. However, you need not always be cheerful – being sad together may be more appropriate than cheerfulness. The patient or family member may need to cry. Even a few tears on your part are normal.

Nursing Home/Assisted Living Facility Guidelines

- **INTRODUCE YOURSELF ON YOUR FIRST VISIT TO PATIENT TO AN ADMINISTRATOR (director of nursing, charge nurse of floor or unit, owner of assisted living or whoever appears in charge.) This is a courtesy and they will see you as part of the hospice team.**
- **Nursing facilities are considered the patients "home" and the staff "extended family".**
- **Caregivers at the facility may need your understanding and support as much as the patients natural family does.**
- **Because of the turnover at nursing facilities, each new nurse or aide may need additional education about hospice care. If you have concerns contact Debbie.**
- **It is appropriate to inform a facility nurse about concerns you may have regarding patient's physical or emotional symptoms; soiled bed or clothes. However, your role is observer and we ask that you not confront facility staff if they don't respond to your inquiries, or make judgments about their care of patients. Always contact the hospice office following your visit and report your concerns. DO NOT WRITE NOTES IN MEDICAL CHART**
- **Volunteers do not have a role in medications. If a family member has questions about any medication, refer them to the facility nurse or have them contact the hospice nurse. If you have concerns contact Debbie or the hospice nurse on-call.**
- **Do not assist non-hospice patients in the facility (i.e. assisting out of bed, transfers, walking, eating). This is a liability issue. Find a nurse to help a non-hospice patient.**
- **Wear your ID badge at all times**
- **Remember to contact family member and offer emotional support if appropriate.**

The Medicare Hospice Benefit

Who is eligible for the Medicare Hospice Benefit?

Medicare coverage for hospice care is available to:

- Patients eligible for Medicare Part A
- The patient must sign a statement choosing hospice care instead of the standard Medicare benefits for the life limiting illness. The hospice care must be from a Medicare-approved hospice program. The patient's physician must certify that the patient has an illness with a life expectancy of six months or less.

What is covered under the Medicare Hospice Benefit?

Hospice care is a unique individualized plan of care suited to the patient's family's needs. The comprehensive services covered include:

- Physician services
- Nursing care
- Medical supplies and equipment related to the life limiting illness
- Prescriptions related to the life limiting illness for symptom management and pain relief
- Short term, acute inpatient care, including respite care
- Medical social services
- Hospice aide services
- Physical and occupational therapy
- Speech/language pathology services
- Dietary and other counseling
- Spiritual counseling
- Volunteer services

Carroll Hospice is a Medicare certified program. Medicare pays hospice directly for the cost of all reasonable and necessary medical and support services for the management of a life limiting illness. The patient and/or family will not receive a bill for covered services.

How long can hospice care continue?

Special benefit periods apply to hospice care. A Medicare beneficiary may elect to receive hospice care for two 90-day benefit periods, followed by an unlimited number of 60-day periods. Hospice patients must still be evaluated and recertified at the end of each benefit period. A patient has the right to cancel hospice care at any time and return to standard Medicare coverage.

Can other Medicare services be received while on the Medicare Hospice Benefit?

Even though the hospice team includes a physician, patients can continue to use their personal physician. Medicare will help pay for covered services provided by a physician not affiliated with the hospice if the patient is covered by Medicare Medical Insurance (Part B). Also, if the patient has Part B, he or she can use all appropriate Part A and B benefits for the treatment of health problems unrelated to the terminal illness. When standard benefits are used, the patient is responsible for Medicare's deductible and coinsurance amounts. Carroll Hospice is not responsible for treatments unrelated to the life limiting diagnosis or treatments that are not palliative in nature.

COMMONLY ASKED VOLUNTEER QUESTIONS

This is a list of actual questions asked by new hospice volunteers of our panel discussion groups. We can use this list to facilitate some discussion.

- How/when is hospice care explained to the patient?
- Does the patient always know what hospice care is? Do they always know they are terminal?
- How does the psychological mindset switch from curative care to palliative care?
- How do you answer a patient who asks you "What does terminal mean"?
- Does the whole family know what hospice is and why we're there?
- What if the patient begins to feel better and thinks they're getting better?
- How often do you see the patient?
- What does a patient want from a social worker and what do social workers offer patients?
- Can a patient see both the Gilchrist Hospice Care chaplain and their own clergy? How does it work?
- How do we handle family members who don't agree with hospice philosophy?
- What happens if the patient dies while I'm there? (Do not call 911).
- What is the benefit of volunteers attending team meetings?
- Is it o.k. for a volunteer to call a nurse/social worker/chaplain? (yes, if there is an issue and you cannot reach the Volunteer Office).
- Who talks to the patients and families about insurance issues?
- What do the team members expect from the volunteers?
- Can volunteers accept gifts from patients/families?

EMERGENCY SCENARIOS AND THE VOLUNTEER RESPONSE

1. The patient dies while you are providing respite care for the caregiver.
   What would you do?

   Call the Carroll Hospice office, 410-871-8000 and follow instructions of the nurse or management person available. ***DO NOT CALL 911.***

2. The patient is due a dosage of medication; the primary caregiver did not leave instructions and set out the medications; the patient is in pain and demands that you get the medication out of the bottle and administer to him/her.
   What would you do?

   Calmly inform the patient that you are not allowed to give medication; call the Carroll Hospice office, 410-871-8000 and follow the instructions of the nurse or management person available.

3. The patient is severely agitated, hallucinating, thrashing about, and crying uncontrollably. You feel overwhelmed and in possible danger.
   What would you do?

   If you feel your personal safety is at risk, stay out of the patient's "personal space" (about 4-6 feet). Call the Carroll Hospice office, 410-871-8000 and follow the instructions of the nurse or management person available.

4. The primary caregiver falls as he/she is preparing to leave for an errand; he/she is a large person, but weak and unable to get up.
   What would you do?

   Call the Carroll Hospice office, 410-871-8000 and follow the instructions of the nurse or management person available. Within 24 hours, the Volunteer Coordinator will ask for a detailed accounting of the incident for a report.

5. You smell smoke and suspect something may be burning or a fire may be about to start.
   What would you do?

   CALL 911 IMMEDIATELY! Follow instructions of the fire department. If possible assist patient to vacate premises and request a neighbor to call Carroll Hospice, 410-871-8000. DO NOT REMAIN IN THE HOME! If the patient cannot be moved and you have time, seal windows and close doors to patient area and LEAVE THE HOUSE. YOUR SAFETY COMES FIRST, ALWAYS!

A Volunteer Remembers Her First Hospice Visit

by Lauren Thibodeau

"Death is beautiful. It alone gives love its true habitat."
Jean Anouilh

A handsome well-dressed middle-aged couple met me as I entered the dimly lit family room late one afternoon. To my right, a bedridden woman, the mother of the man I just met, slept fitfully in a hospital bed. Her name was Helen and she was my first hospice patient.

I was far from brave. Was I ready?, I asked myself. Would I know what to do? Was the family aware that their beloved Helen would spend the next five hours with a novice volunteer, well-meaning yet untried - and slightly terrified? A silent prayer, a hard swallow; I was ready. I had to be.

I listened quietly to the couple's instructions as I followed them up the half-flight of stairs to the kitchen where important phone numbers were taped to an old-fashioned rotary dial phone. The refrigerator held soft foods Helen could still manage to eat, they told me. They also noted that tiny morphine tablets in a brown prescription bottle were set out on the kitchen counter.

I looked around as the couple explained things. On the living room coffee table was an anniversary card artfully decorated with red roses. It was from Walter, Helen's husband of 38 years. "To My Wife," said the gold script on the card. That evening, Walter hadn't wanted to leave his wife's side. But he needed a break and he had been persuaded to let me sit with her for the evening. He was out bowling with his team. Walter wasn't the only one "in love" with Helen, however. Signs of true caring were everywhere in the house. Glancing across the living room, I noted many photos and cards that were strewn next to the anniversary card, as if they had just been reread.

Eventually, I followed Helen's son, his wife and Helen's devoted dog, Benji, back to the family room. There was a change: Helen's breathing now alternated from shallow to gasping. My volunteer training told me that this suggested death was near. I also sensed that Helen's family was not fully prepared to accept her imminent death, as her cancer had not been diagnosed for very long. What did her changing breathing patterns mean?, they wanted to know. I answered carefully, gently suggesting what I had learned in my training. I also encouraged them to speak with hospice medical staff.

As Helen temporarily settled down, I tried sitting and reading a mystery novel by low light. But I couldn't concentrate. I felt Helen's spirit and her coming death. Suddenly, despite months of training, I didn't feel ready to be a hospice volunteer. What if Helen's labored breathing stopped?, I wondered. Unsure of myself, part of me wanted Helen to go on living.

Walter returned shortly before 10 p.m. Although he is a tall, strong man, lifting Helen to a new position required our combined efforts. My training in moving and turning patients was very helpful because Helen was unable to sit up or open her eyes fully. After we moved her, she leaned back into Walter's arms as he gently stroked her head. "You've always had such beautiful hair," he whispered. "You are very beautiful."

I looked away with tears in my eyes, in part embarrassed to be intruding on such an intimate moment. Yet, I also felt honored to be in Helen's presence; I felt wonder over the opportunity to be with another human being, to quietly pray for her, to gently love her although I never knew her, and to shed tears because I never knew her.

The next time I saw Helen was at her wake. She died less then 48 hours after that night I was with her, with Walter and Benji at her side. At the funeral home, her anniversary card and a red rose had been lovingly tucked under her hands. Her hair was neatly coiffed, and she wore a pleated pink gown.

Looking back, I think I must have been more prepared as a hospice volunteer than I realized, because my experience with Helen and her family turned out to be so emotionally and spiritually rewarding. Love, grace and peace can be a part of death, Helen taught me, and that is a lesson I will not soon forget.

Hospice, Spring 1995

Lauren Thibodeau volunteers with Hospice of the Western Reserve, Cleveland, Ohio

Complimentary

COMPLIMENTARY THERAPIES

OVERVIEW

Hospice philosophy encourages the use of "complimentary" therapies to help patients/families cope with physical or emotional pain. This section introduces some of the different ways in which a hospice patient may find pain relief or comfort.

LEARNING OBJECTIVES

By the end of this session, the participants will be:

1. Encouraged to open their minds to complimentary methods of pain control and relief of emotional stress.
2. Able to recommend these methods to their patients and will know how to access the appropriate therapist.

Healing Touch

(Reiki is a similar modality)

Carole Baillet, Volunteer

Healing Touch is an energy modality for directing energy to areas that are in need of healing. This can be areas afflicted with cancer or disease and areas ravaged by radiation therapy and the after effects of chemotherapy or medications and surgery. It can also be beneficial to help in healing broken bones, depression, grief, and behavior disorders. It is often helpful in reducing pain, decreasing anxiety, apprehension and restlessness.The Healing Touch Practitioner places hands in various positions, depending upon the affliction or affected area, and with intent and focus, directs and facilitates healing energy. My use of Healing Touch with Hospice patients has been extremely rewarding. It seems to bring peace and calm to agitated and restless patients. One patient in particular comes to mind. I could hear him yelling out in pain from his room all the way to the volunteer's desk. I asked if I could go in and perform Healing Touch on him and was given permission. My heart went out to him and the family member sitting by his side. I sat at his other side and began to treat him. Within a few minutes he calmed down. As I treated him I asked if he would like to pray and he told me "Yes, please". We prayed the Lord's Prayer as he received Healing Touch. When we finished he went right to sleep. Another patient that is brought to mind is a gentleman who was determined to get out of bed and was very angry and agitated that he wasn't allowed to because of his condition. Of course that wasn't going to stop him from trying and fighting with anyone who wouldn't let him. Maybe it was due to his level of agitation, I don't know, but the medications he had been given to help him calm down and rest weren't working yet. I again asked if I could do Healing Touch and he told me "oh, alright." It seemed I had no sooner begun and then he was snoring loudly. One elderly lady patient of mine in a nursing facility had complained of pain in her foot. Using Healing Touch on the ball of her foot and at her heel, "worked like a miracle" (her words). Now I treat her regularly when I am there. Using Healing Touch is totally non-invasive. It is very calming and peaceful and many times the recipient falls asleep as the treatment is going on. A sense of well-being and a loving energy are felt by many. As a result of its recognized effectiveness Healing Touch is now becoming a mainstream treatment in a lot of major hospitals. Some hospitals are requesting their nursing staff to become trained in it. As more clinical trials are performed its acceptance will likely increase. I am very thankful to be a part of it.

PATIENT-TEACHING AID

How to do relaxation breathing exercises

Dear Patient:

Relaxation breathing can help you cope with stress or pain. You can use it anywhere and at any time. You can also combine it with other techniques to help control pain. Try to practice these simple breathing techniques daily. Now, get comfortable and begin.

1 Close your eyes. Inhale slowly and deeply through your nose as you count silently: "In, 2, 3, 4." Notice how your stomach expands first, then your rib cage, and finally your upper chest.

Now exhale slowly through your mouth as you count silently: "Out, 2, 3, 4, 5, 6." Pretend you're breathing out through a straw to lengthen exhalation.

Let your shoulders drop slightly as your upper chest, rib cage, and stomach gently deflate.

Repeat this exercise four or five times.

2 Inhale for 4 seconds. Hold your breath for the count of 4, but don't strain. Then exhale through your mouth for 6 to 8 seconds. Practice this exercise four or five times.

A few tips

Use these breathing exercises for as long as you need to during painful periods. You may vary the rhythm, but always exhale for 2 to 4 seconds longer than you inhale.

If you feel light-headed or your fingers tingle, you may be breathing too deeply or too fast. Reduce the depth and speed of your breathing, or breathe into a paper bag until the feeling goes away.

PATIENT-TEACHING AID

Using your imagination to control pain

Dear Patient:

How would you like to take a mental vacation? Well, you can if you let your imagination be your guide.

1 Begin by focusing on your breathing. Spend a few minutes breathing slowly and smoothly.

2 As you breathe, slowly count backward from 5, sinking deeper and deeper into a state of relaxation. Say to yourself, "I feel deeply relaxed."

3 Next, imagine a pleasant place that you can return to whenever you need relaxation or pain relief—for example, a warm, quiet beach or a tranquil, fragrant garden. Close your eyes to help you concentrate.

4 "Experience" the place with all your senses—sight, touch, smell, hearing, and taste. Remain there for about 5 minutes or longer, depending on the time you need for pain relief.

Let your imagination run free. Try to name the colors you see. Or trace the shapes of the flowers blooming in the garden. Breathe in the sweet fragrance of the blossoms, listen to the birds chirping, and feel the sun warm your skin. Now, sip a cool beverage before you step along the garden path and greet a friend.

5 Slowly let the image you've chosen fade from the center of your attention as you focus again on your breathing. Maintain a relaxed feeling. When you feel ready, count slowly to 5 and open your eyes.

PATIENT-TEACHING AID

How to give a back massage

Dear Caregiver:

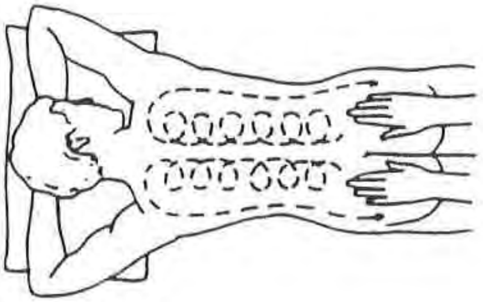
Before giving a back massage, make sure your nails are trimmed and your hands are warm. Then follow these steps. (You can also use these techniques on other body areas.)

1 Position the person on his stomach or side, with his back exposed. The room should be comfortably warm so that he doesn't become chilled.

2 Apply a nonoily lotion to the person's skin to reduce friction. Warm the lotion first by placing the bottle in a bowl of warm water.

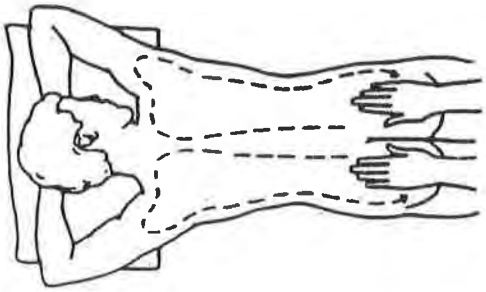
Tell the person to imagine his muscle fibers stretching and relaxing as you massage.

3 Start with gentle strokes and gradually apply pressure, as tolerated. Using a circular thumb stroke, massage from the buttocks to the shoulders. Then, using a smooth stroke, return to the buttocks.

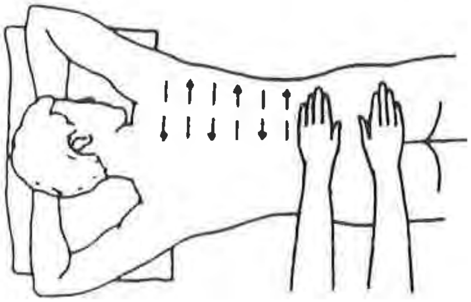


Be sure to keep your hands in line with the spine to avoid tickling the person.

4 Next, using your palms, stroke from the buttocks up to the shoulders, over the upper arms, and back to the buttocks. Use slightly less pressure on downward strokes.



5 Using your thumb and forefinger, knead and stroke the left side of the back and the upper arm, starting at the buttocks and moving toward the shoulder. Then knead and stroke the right side of the back, rhythmically alternating your hands. Massage for 3 to 5 minutes or longer, as tolerated.



Physical contact is not only therapeutic — it can be life-altering, shows new research into …

The power of TOUCH

BY TOM McNICHOL

A MAN GENTLY BRUSHES his hand across the cheek of his lover. A mother cradles her infant. A football player hugs a teammate after a touchdown.

Only now is science beginning to catch up with humanity when it comes to appreciating the importance — and the power — of touch. The University of Miami School of Medicine's Touch Research Institute (TRI) brings together researchers from Duke, Harvard, Princeton and other universities to study the sense of touch and how it might be used to promote health and treat disease. So far, TRI has uncovered surprising evidence that touch doesn't simply feel good — it can actually heal.

Among the institute's findings:

■ Touch can lift depression. A 30-minute back massage given daily for five days to hospitalized, depressed and adjustment-disorder children reduced their depression, decreased stress hormones and improved sleep.

Premature infants who get regular massages in the hospital gain more weight and leave the hospital sooner than unmassaged babies.

■ Massage therapy increases immune function, particularly significant for people infected with HIV. Subjects receiving four weeks of massage therapy had increased immune function and lower stress hormone levels.

■ Massage also reduces job stress, which costs the United States an estimated $200 billion each year through diminished productivity, worker compensation claims, absenteeism and direct medical expenses. Adults were given 15-minute massages in their office, twice a week for four weeks. Immediately after the massage sessions, the employees experienced heightened alertness and performed better on math problems.

■ Premature infants subjected to a gentle 15-minute massage three times a week showed remarkable improvement over preemies left untouched in their incubators. Massaged infants gained weight 47 percent faster, had better motion response and were released from the hospital six days sooner, saving thousands of dollars per infant.

"Hospitals usually handle premature infants as little as possible," says Maria Hernandez-Reif, director of TRI's massage therapy research project. "But we've found that the right sort of touch can be very beneficial."

■ Autistic children, who often show an aversion to touch, can actually benefit from massage therapy. A group of autistic children were given a half-hour massage two times a week for five weeks. At the end of the study, the massaged children showed significantly less "off-task" behavior and better social relations with their teachers.

Compared with other cultures, Americans are touch-deprived. Cross-cultural studies have revealed that the United States has one of the lowest rates of casual touch in the world — about two times an hour (although the same does not hold for Puerto Ricans, who claim one of the highest rates of casual touch — about 180 times an hour). French parents touch their children three times more often than American parents.

Americans are relatively touch-deprived, studies show. French parents touch their kids three times more often than American parents.

And, in spite of a new and growing body of evidence that touch is good for both soul and body, escalating concerns about "inappropriate" touch and sexual abuse have made Americans touchier about touch than ever. Some schools have instituted "teach, don't touch" policies.

"You seldom see a teacher put his hands on a child's shoulder who is crying anymore," says Harville Hendrix, author of the best-selling book *Getting the Love That Heals: A Guide for Parents*. "That's a real loss. To protect ourselves from being accused of inappropriate touch, we're not touching at all."

In many ways, human beings are wired for touch. The skin is the body's largest organ, covering almost 20 square feet and accounting for nearly one-quarter of the body's total weight. Touch is the first sense to develop in humans and is usually the last to fade. Researchers at TRI say a daily dose of touch can be as essential to good health as diet and exercise.

Touch is a cheap and effective prescription for wellness. For those without a willing partner to hug or touch them, touch can be self-administered on the hand or foot, or by using a self-massage device.

"Touch is often seen as a taboo in our culture, but that's only because we've forgotten our early ways," Hernandez-Reif says. "Touch is one of our earliest forms of healing. We need to get back to that." W

Contributing Editor Tom McNichol last wrote for USA WEEKEND's fifth annual report on the nation's Most Caring Athletes.

Healing gift of humor shouldn't be taken lightly

"Laughter is a tranquilizer with no side effects."

— Arnold Glasgow

Scripps Howard News Service

Twenty-five years ago, Thelma Hembroff had to teach herself to smile. Today the minister at Unity Christ Church gives workshops on the healing power of humor.

"When I was in high school, I decided to emulate my principal who never smiled," said Hembroff, 55. She smiled so rarely that people would ask her if she was unhappy. She wasn't.

"I decided to practice smiling," she said. "It hurt at first because my face muscles hadn't been used."

Today she not only smiles easily, she makes sure she belly-laughs often. And she tries to get others to do it, too, through the "Humor, Healing, Risk and Change" workshops she teaches for the continuing education department at the University of Memphis in Tennessee.

"The people in my classes have found that humor has gone out of their lives for one reason or another," Hembroff said. "Sometimes it's because of the break-up of a relationship; some have been sick, others are around someone who is ill."

One of her workshop exercises involves playing a tape of laughter and asking the students not to laugh. In a few seconds, everyone is cracking up.

"Even if there's nothing to laugh about, laugh on credit."

— Anonymous

Going to a class to learn to laugh might seem odd to people who do it effortlessly. But it completely changed the life of 18-year-old Alicia Forrest.

"Before I took the class I was a very serious person," Alicia said. "I would never catch a joke and now I'm making them right and left."

Alicia said her inability to adjust to stress and change caused her to plunge into a depression. It happened four years ago when her sister, with whom she is very close, went away to college and her mother remarried and moved the family to another house. Laughter became a rare occurrence for her.

"The big joke around here now is 'who is this person' who is laughing and joking," Alicia said. "I'm hoping the change is permanent."

"A person who belly-laughs doesn't bellyache."

— Susan Thurman

Hembroff said laughter comes from various places in the body. "Tee-hees" are from the head; "ha-has" from the chest and "ho-hos" from the belly.

It's the ho-hos or belly laughs that are the most therapeutic. "Exercise is good for stress relief, but a good belly laugh is like exercising the inside of your body," Hembroff said.

Laughter has been found to:

- ■ Increase the heart rate and improve circulation
- ■ Stimulate respiratory activity
- ■ Relax muscles
- ■ Improve digestion
- ■ Cause secretions of alertness hormones

"By being frequently in the company of children, we may learn to recapture the will to laugh and art of laughing at will."

— Julius Gordon

Two Memphis hospitals that specialize in the treatment of children find humor is healing in several ways.

"We know that children can have a decreased perception of pain when they are laughing," said Dr. Glenn Ann Martin, manager of behavioral health and psychology at Le Bonheur Children's Medical Center. "And humor is a tremendous factor for the caregivers on the front lines."

In stress management workshops for Le Bonheur employees, humor is seen as an effective release valve.

Both Le Bonheur and St. Jude Children's Research Hospital operate child life departments that provide play activities for their patients aimed at reducing stress and anxiety.

"Kids naturally have a sense of humor and optimism," said Joan McGill, child life director at St. Jude. "Play is the way kids learn."

"Suffering makes you laugh, too."

— Yiddish proverb

The late Norman Cousins, longtime editor of the *Saturday Evening Post*, helped draw attention to the power of humor with the publication of his book "Anatomy of an Illness."

He decided on an innovative self-treatment plan when he was given a 1 in 500 chance of recovering from a life-threatening form of arthritis. He refused pain-killing drugs, took megadoses of Vitamin C and replaced negative thoughts with humorous ones. He was able to laugh by watching old Candid Camera programs and funny movies featuring the Marx brothers and Laurel and Hardy.

Safety

CARROLL
HOSPITAL CENTER

Title: Standard Precautions	Effective Date: 3/19/2013
Document Owner: Barbara Juzaitis	
Approver(s): Bridget Krautwurst, Mary Ann Kowalczyk, Paul Eder, Robert White, Stephanie Reid, Syed Hosain	

Printed copies are for reference only. Please refer to the electronic copy for the latest version.

I. Purpose: **To reduce the risk of transmission of microorganisms from both recognized and unrecognized sources of infection in the hospital.**

II. Policy Statement/Philosophy:

1. Standard Precautions applies to all patients regardless of their diagnosis and are based on the principle that potentially infectious materials may contain transmissible infectious agents.
2. Standard Precautions will be implemented when contact with any of the following is anticipated:
   - Blood
   - All body fluids, secretions, and excretions *except sweat*, regardless of whether they contain visible blood
   - Non-intact skin
   - Mucous membranes
   - Potentially contaminated intact skin

III. Procedure:

1. Hand Hygiene
   - When hands are visibly dirty, contaminated with proteinaceous material, or visibly soiled with blood or body fluids, wash hands with either a nonantimicrobial soap and water or an antimicrobial soap and water.
   - If hands are not visibly soiled, decontaminate hands in the clinical situations described below. The preferred method of hand decontamination is with an alcohol-based hand rub (Quik-Care). Alternatively, hands may be washed with an antimicrobial soap and water. Perform hand hygiene:
     - Before having direct contact with patients.
     - After contact with blood, body fluids or excretions, mucous membranes, nonintact skin, or wound dressings.
     - After contact with a patient's intact skin (eg, when measuring pulse or blood pressure or lifting a patient).
     - If hands will be moving from a contaminated body site to a clean body site during patient care.
     - After contact with inanimate objects (including medical equipment) in the immediate vicinity of the patient.
     - After removing gloves.
   - Wash hands with soap and water if contact with spores (eg, *C difficile* or *B anthracis*) is likely to have occurred. The physical action of washing and rinsing hands under such circumstances is recommended because all antiseptic agents have poor activity against spores.
   - During delivery of health care, avoid unnecessary touching of surfaces in close proximity to the patient, to prevent contamination of hands and transmission of pathogens.

2. Gloves
   - Wear gloves when it can be reasonably anticipated that contact with blood or other potentially infectious materials, mucous membranes, nonintact skin, or potentially contaminated intact skin (eg, of a patient incontinent of stool or urine) could occur.
   - Gloves must be worn when performing venipuncture and other vascular access procedures.
   - Wear gloves with fit and durability appropriate to the task.
   - Remove gloves after contact with a patient and/or the surrounding environment (including medical equipment) using proper technique to prevent hand contamination. Do not wear the same pair of gloves for the care of more than 1 patient.
   - Change gloves during patient care if the hands will move from a contaminated body site (eg, perineal area) to a clean body site (eg, face).
   - Gloves must be removed promptly after use, before touching non-contaminated items and surfaces, and before going to another patient.

3. Gown
   - A disposable gown must be worn to protect skin and to prevent soiling or contamination of clothing during procedures or patient-care activities that are anticipated to generate splashes or sprays of blood, body fluids, secretions, or excretions.
   - Remove gown and perform hand hygiene before leaving patient's environment.

4. Mask, Eye Protection, Face Shield
   - Mask and eye protection or a face shield must be worn to protect mucous membranes of the eyes, nose and mouth during procedures or patient-care activities that are expected to generate splashes or sprays of blood, body fluids, secretions, or excretions.
   - During aerosol-generating procedures (eg, bronchoscopy, suctioning of the respiratory tract [if not using in-line suction catheters], endotracheal intubation) wear one of the following: a face shield that fully covers the front and sides of the face, a mask with attached shield, or a mask and goggles (in addition to gloves and gown).

5. Patient-Care Equipment
   - Patient-care equipment that has been soiled with blood, body fluids, secretions, and/or excretions must be handled in a manner that prevents skin and mucous membrane exposure, contamination of clothing, and transfer of microorganisms to other patients or the environment. This requires the use of personal protective equipment while handling and the appropriate disinfection and/or sterilization.
   - Reusable equipment that has come in contact with non-intact skin, blood, body fluids, or mucous membranes, must be cleaned with a hospital-approved disinfectant before it is used for the care of another patient. Do not place this equipment in another patient room or the clean utility area until it has been properly cleaned.
   - Any patient care equipment that is sent from any department for repair or service should be cleaned with a hospital-approved disinfectant prior to transport.

6. Linen
   - Linen soiled with blood, body fluids, secretions or excretions must be handled in a manner that prevents skin or mucous membrane exposure, contamination of clothing, and transfer of microorganisms to other patients and the environment. This requires the use of personal protective equipment. Dispose of all soiled linen in a "soiled linen bag". Never place soiled linen on the floor or any clean surface.

7. Waste
   - All special medical waste is placed in a red plastic bag at least 3 ml thick. (See Facilities Management Procedure Disposal of Special Medical Waste)

8. Occupational Health and Bloodborne Pathogens
   - Extreme caution should be taken to prevent injuries when handling needles, scalpels, and other sharp instruments or devices by promptly disposing of them in the approved sharps container.
   - Never recap used needles, or use any other technique that involves directing the point of a needle or sharp toward any part of the body. If recapping is clinically necessary, use a one-handed "scoop" technique or a mechanical device designed for holding the needle sheath. Do not remove used needles from disposable syringes by hand.
   - Do not bend, break, or otherwise manipulate used needles by hand.
   - Only hospital-approved sharps safety devices are to be used.
   - Use mouthpieces, resuscitation bags, or other ventilation devices as an alternative to mouth-to-mouth resuscitation methods for resuscitation.
   - Hepatitis B vaccine is available, free of charge, to persons working with patients or materials that may contain the hepatitis B virus. Healthcare workers (HCW) must receive the vaccine or sign a declination form. Vaccination is available by calling the Associate Health Office at ext. 6846.
   - If a healthcare worker is stuck with a needle/sharp or splashed in the eyes, mouth, or other mucous membrane with blood or other potentially infectious material, this incident is to be reported to the exposed HCW's supervisor immediately. The supervisor and the HCW will promptly complete the *Associate Illness and Injury Report* form. The Associate Health Nurse or designee will manage the "exposure incident". (Refer to policy Needlestick and Other Bloodborne Pathogen Exposure Follow-Up)

9. Patient Placement
   - Include the potential for transmission of infectious agents in patient placement decisions. Place patients who pose a risk for transmission to others (eg, those with uncontained secretions, excretions, or wound drainage; infants with suspected viral respiratory or gastrointestinal infections) in a single-patient room when available.
   - Determine patient placement based on the following factors:
     - Route(s) of transmission of the known or suspected infectious agent
     - Risk factors for transmission in the infected patient
     - Risk factors for adverse outcomes resulting from an HAI in other patients in the area or room being considered for patient placement
     - Availability of single-patient rooms
     - Patient options for room sharing (eg, co-horting patients with the same infection)

10. Respiratory hygiene/cough etiquette
    - Implement the following measures to contain respiratory secretions in patients and accompanying individuals who have signs and symptoms of a respiratory infection, beginning at the point of initial encounter.
    - Post signs at entrances and in strategic places within ambulatory and inpatient settings with instructions to patients and other persons with symptoms of respiratory infection to cover their mouths and noses when coughing or sneezing, use and dispose of tissues, and perform hand hygiene after hands have been in contact with respiratory secretions.
    - Provide tissues and no-touch receptacles for disposal of tissues.

- Provide resources and instructions for performing hand hygiene in or near waiting areas in ambulatory and inpatient settings; provide conveniently located dispensers of alcohol-based hand rubs and, where sinks are available, supplies for handwashing.
- During periods of increased prevalence of respiratory infections in the community (as indicated by, eg, increased school absenteeism, increased number of patients seeking care for respiratory infection), offer masks to coughing patients and other symptomatic persons (eg, persons who accompany ill patients) on entry into the facility, and encourage them to maintain special separation (ideally, at least 3 feet) from others in common waiting areas.

11. Safe injection practices

The following recommendations apply to the use of needles, cannulas that replace needles, and, where applicable, intravenous delivery systems.

- Use aseptic technique to avoid contamination of sterile injection equipment.
- Do not administer medications from a syringe to multiple patients, even if the needle or cannula on the syringe is changed.
- Use single-dose vials for parenteral medications whenever possible.
- If multidose vials must be used, both the needle or cannula and syringe used to access the multidose vial must be sterile.
- Do not keep multidose vials in the immediate patient treatment area. Store in accordance with the manufacturer's recommendations; discard if sterility is compromised or questionable.
- Do not use bags or bottles of intravenous solution as a common source of supply for multiple patients.

12. Care of the environment

- Clean and disinfect surfaces likely to be contaminated with pathogens, including those in close proximity to the patient (eg, bed rails, over bed tables) and frequently touched surfaces in the patient care environment (eg, door knobs, surfaces in and surrounding toilets in patient rooms) on a more frequent schedule compared with that for other surfaces (eg, horizontal surfaces in waiting rooms).
- Use EPA-registered disinfectants that have microbiocidal (ie, killing) activity against the pathogens most likely to contaminate the patient care environment. Use in accordance with manufacturer's instructions.

IV. Responsibility: Applicable to all hospital associates, physicians, volunteers & students.

CARROLL
HOSPITAL CENTER

Title: Hand Hygiene	Effective Date: 4/22/2010
Document Owner: Barbara Juzaitis	
Approver(s): Bridget Krautwurst, Kevin Smothers, Mary Ann Kowalczyk, Mokhtar Nasir, Paul Eder, Stephanie Reid, Syed Hosain	

Printed copies are for reference only. Please refer to the electronic copy for the latest version.

Purpose: To provide guidelines for proper hand hygiene to aid in the prevention of healthcare-associated infection.

Policy: Only the hospital-approved hand hygiene agents are to be used.

A. Associates must wash hands with soap and water:
  - When hands are visibly soiled or contaminated.
  - When caring for a patient with C.difficile, soap & water is preferred.
  - After using a restroom.

B. Associates must wash hands or apply a waterless hand antiseptic:
  - Before having direct contact with a patient.
  - Before donning sterile gloves when inserting indwelling catheters, peripheral vascular catheters, or other invasive devices that do not require a surgical procedure.
  - After contact with a patient's intact skin (taking a pulse, BP, or lifting a patient).
  - After contact with body fluids or excretions, mucous membranes, non-intact skin, and wound dressings, if hands are not visibly soiled.
  - When moving from a contaminated-body site to a clean-body site during patient care.
  - After contact with inanimate objects in the immediate vicinity of the patient.
  - After removing gloves.

C. Operating Room associates will observe the "Surgical Hand Scrub" policy for their specific area.

D. Food Service associates will observe their departmental policy "Personnel Practices- Infection Control".

E. Associates must comply with the fingernails policy noted in the Human Resources Policy titled "Attire and Appearance".

F. Employees with sensitivities to the hospital-approved hand washing/antiseptic agents shall consult with the Associate Health Nurse.

G. Dermatitis of the hands should be evaluated by the Associate Health Nurse before delivering patient care.

Procedure/Process/Guidelines:

A. **Hand Washing**
   1. Have paper towels available that you will use to dry your hands. If you have to touch a container or knob to get the towel, do so before you wash your hands.
   2. Wet hands with warm water.
   3. Put soap on hands.
   4. Vigorously lather hands and rub them together for at least 10-15 seconds. Wash between your fingers, the backs of your hands, your thumbs, and under your fingernails.
   5. Rinse hands thoroughly and dry with a paper towel.
   6. Turn off faucets with the paper towel.

B. **Waterless Hand Antiseptic**
   1. Apply waterless hand antiseptic to hands.
   2. Rub product onto all surfaces of the hand, paying particular attention to the tips of the fingers, the thumbs, and the areas between the fingers.
   3. Continue rubbing until the solution has evaporated and the hands are dry.

References:

1. CDC, "Guideline for Hand Hygiene in Health-Care Settings." MMWR October 25, 2002, Vol 51, No RR-16.
2. Larson, El, APIC Guidelines Committee. "APIC Guidelines for Handwashing and Hand Antisepsis in Health Care Settings." AJIC 1995, 23:251-269.
3. CDC Hospital Infection Control Practices Advisory Committee. "Guidelines for Prevention of Surgical Site Infections, 1999.", AJIC 1999,Vol 27, No 3:97-127.
4. J C Hand Hygiene

DOVE HOUSE FIRE SAFETY
CODE RED

R.A.C.E. (fire response)

- **R** = Rescue
- **A** = Alarm
- **C** = Confine
- **E** = Extinguish

Roles and Responsibilities

- Rescue anyone in immediate danger of fire and smoke
- Close all doors
- Clear corridors of obstructions

Types of Evacuation

- Horizontal - move patient away two or more fire separations
- Vertical - move patient to another floor
- Total - move out of the building

Fire Extinguisher Locations

- Dove House (upstairs):
  - Kitchen
  - Near the elevator
  - Hallway outside of the nurse's station
  - Hall by room 4
  - Finished meeting area
- Administrative Area (downstairs):
  - Hallway of the Executive Director's office
  - Kitchen
  - Hallway as you enter the clinical area
  - Next to the mailboxes
  - Finance area

Check the building and be familiar with the extinguisher locations!

P.A.S.S. (fire extinguisher operation)

- **P** = Pull the pin
- **A** = Aim at the base of the fire
- **S** = Squeeze the handle
- **S** = Sweep across the fire

Exhibit 16

Caregivers

(Question 7)

Patient Orientation for Home Hospice

When the Time Comes Booklet

What to Expect at the End of Life Rack Card

Falls Prevention Brochure

Spiritual Care Brochure

Patient Orientation for Home Hospice

CARROLL
HOSPICE

292 Stoner Avenue | Westminster, MD 21157
(410) 871-8000 | TDD: (410) 871-7186 | Toll Free: 1-888-224-2580

4

Patient Orientation for Home Hospice Care

STATEMENT OF CONFIDENTIALITY
This booklet may contain protected health information. Persons other than you and your health care providers must have your permission to view this booklet.

CHAP
EST. 1965

On-Call Guidelines

ON-CALL GUIDELINES

Call (410) 871-8000 at any time.

A registered nurse (RN) is available 24 hours a day, 7 days a week to assist you with problems after regular office hours, on weekends or holidays. We will talk with you by phone to determine your needs. When appropriate, a nurse will come to your place of residence. We are available after regular office hours for urgent conditions.

Do not call 911 before calling the on-call nurse. Should you call 911, this may not be a covered hospice expense. The following is a list of some reasons for which you may need to contact us after regular hours. We do not carry medications with us and cannot give anything unless ordered by the physician.

Examples of after-hours situations:

- Pain that does not respond to pain medication on hand
- Difficulty breathing
- New onset of agitation or restlessness
- Falls
- No urine in 8 hours associated with discomfort
- Uncontrolled nausea, vomiting or diarrhea
- Uncontrolled bleeding
- Temperature above 101°F that does not respond to Tylenol®. **Note:** Patients on chemotherapy may be instructed to call before taking Tylenol®.
- Unable to awaken patient (new problem)
- Catheter leaking
- Chest pain
- Patient taken to the hospital
- Patient death

Patient Orientation for Hospice Care

Rev. 2/17

CARROLL
HOSPICE

SECTION I. Welcome and Philosophy

The associates of **Carroll Hospice** feel privileged to provide you with care and services from our agency. Our goal is to work collaboratively with you, your family and your doctor to help you in dealing with end-of-life issues and maintaining a high quality of life.

We are pleased that you have chosen our agency to provide your care. The foundation of good care is good communication. We have developed this handbook for you to use. It provides you with information about procedures, access, our interdisciplinary group members, supplies and equipment and answers questions that you may have during your care.

Carroll Hospice is committed to delivering superior services that are flexible and responsive to the needs of our patients, families and our community. We are a free-standing, not-for-profit hospice affiliated with Carroll Hospital, a LifeBridge Health center. We are Medicare certified, licensed by the State of Maryland and accredited by Community Health Accreditation Partner (CHAP).

Our agency is committed to dialoging with you and your family regarding your rights and choices as a hospice patient. Many aspects of our services may be new to you, so we hope this booklet will assist you in becoming familiar with us as quickly and easily as possible.

We welcome you to our family. We are here for you, to listen and to assist you as you embark on this journey.

Sincerely,

The Staff of Carroll Hospice

LANGUAGE ASSISTANCE SERVICES

Spanish: ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-877-715-0110.

Chinese: 注意：如果您使用繁體中文，您可以免費獲得語言援助服務。請致電 1-877-715-0110。

Korean: 주의: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 1-877-715-0110번으로 전화해 주십시오.

Vietnamese: CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số 1-877-715-0110.

French: ATTENTION : Si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Appelez le 1-877-715-0110.

Tagalog: PAUNAWA: Kung nagsasalita ka ng Tagalog, maaari kang gumamit ng mga serbisyo ng tulong sa wika nang walang bayad. Tumawag sa 1-877-715-0110.

Russian: ВНИМАНИЕ: Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Звоните 1-877-715-0110.

Amharic: ማስታወሻ: የሚናገሩት ቋንቋ ኣማርኛ ከሆነ የትርጉም እርዳታ ድርጅቶች፣ በነጻ ሊያግዝዎት ተዘጋጀተዋል፡ ወደ ሚከተለው ቁጥር ይደውሉ 1-877-715-0110.

Ibo: Ntị: Ọ bụrụ na asụ Ibo, asụsụ aka ọasụ n'efu, defu, aka. Call 1-877-715-0110.

Yoruba: AKIYESI: Bí o bá nsọ èdè Yorùbú ọfé ni iranlọwọ lori èdè wa fun yin o. Ẹ pe ẹrọ-ibanisọrọ yi 1-877-715-0110.

Urdu: خبردار: اگر آپ اردو بولتے ہیں، تو آپ کو زبان کی مدد کی خدمات مفت میں دستیاب ہیں ۔ کال کریں 1-877-715-0110.

Persian (Farsi): توجه: اگر به زبان فارسی گفتگو می کنید، تسهیلات زبانی بصورت رایگان برای شما فراهم می باشد. با 1-877-715-0110 تماس بگیرید.

French Creole (Haitian): ATANSYON: Si w pale Kreyòl Ayisyen, gen sèvis èd pou lang ki disponib gratis pou ou. Rele 1-877-715-0110.

Portuguese (European): ATENÇÃO: Se fala português, encontram-se disponíveis serviços linguísticos, grátis. Ligue para 1-877-715-0110.

Arabic: ملحوظة: إذا كنت تتحدث اذكر اللغة، فإن خدمات المساعدة اللغوية تتوافر لك بالمجان. اتصل برقم 1-877-715-0110.

Gujarati: સુચના: જો તમે ગુજરાતી બોલતા હો, તો નિ:શુલ્ક ભાષા સહાય સેવાઓ તમારા માટે ઉપલબ્ધ છે. ફોન કરો 1-877-715-0110.

SECTION II. Hospice Services

This guide is designed to provide practical information to assist you and your family/caregiver in understanding hospice care. Do not hesitate to ask about anything not covered in this guide.

THE ADMISSION PROCESS

Admission to hospice is made with an order from your physician, based upon your identified care needs. Patients with a life expectancy of 6 months or less, if the illness runs its normal course, are usually appropriate candidates for hospice.

On admission, our nurse will visit you and/or your family at home or in the hospital to discuss hospice services, assess your immediate needs and develop a Plan of Care with you.

SERVICES

Hospice services include: **Nursing, Social Services, Physician Services, Physical, Occupational and Speech Therapy Services, Hospice Aide/Homemaker, Volunteer Services and Spiritual, Dietary and Bereavement Counseling**. All services are provided under the direction of a physician of your choice and/or the Carroll Hospice Medical Director.

Arrangements will be made for needed medical supplies and equipment, as appropriate.

In most cases, your insurance company will pay hospice directly; however, not all insurance plans provide full coverage for hospice care and some hospice services may not be covered under your plan. We receive our reimbursement from Medicare, Medicaid and private health insurance for services. All third party payors are billed for hospice services as appropriate. **No patient is refused care due to lack of financial means to pay for services.** All patients, who meet the requirements, are accepted regardless of ability to pay. Our social worker will meet with the patient/family to determine concerns and needs.

Prior to, or on admission, you or your guardian, caregiver or family member will be informed of all charges for services provided and methods of payment. If changes occur and hospice is unable to meet your needs in your current environment, an alternative Plan of Care will be developed in collaboration with you, your family and your physician.

Should any change be made regarding services or charges, you or your responsible party will be advised.

THE ROLE OF THE HOSPICE STAFF

Nurse Case Manager: You will be assigned a Registered Nurse (RN) Case Manager who will coordinate your care with other members of the interdisciplinary group. The role of the nurse is to help prevent and relieve pain and other symptoms, and to teach caregivers ways to provide for your care. Medical supplies and equipment will be ordered and monitored appropriately. Ongoing communication with your physician will be provided as any change in your condition occurs. Your hospice nurse will try to anticipate your needs and assist you and/or your caregiver in a better understanding of the progression of your illness.

Your nurse will set up a regular visit schedule according to your individual needs. He/she will be available and accessible from 8:00 a.m. to 4:30 p.m., Monday through Friday. You can reach your nurse by calling Carroll Hospice at **(410) 871-8000**.

Social Worker: Facing a serious illness can be a time of sadness and confusion for you and your family members. To help you and your family better cope with the emotions and challenges throughout the time in which your illness is occurring, a hospice social worker will be provided.

Services that are available by the social worker include:

- Emotional support, counseling and guidance to you and your family in coping with stress related to your illness;
- Identifying community resources which may be available to you;
- Assist you and your family members to access in-home support or an alternative; and
- Offer information concerning Advance Directives such as, Living Wills and/or Durable Power of Attorney for Health Care.

Physician Services: The hospice medical and contracted physician(s) of the hospice, along with your attending physician are responsible for the palliation and management of your terminal illness and any other conditions related to the terminal illness. If your attending physician is not available, the hospice medical or designee is responsible for meeting your medical needs.

Physical, Occupational and Speech Therapists: Services are provided by a licensed therapist or licensed therapy assistant under the direction of the therapist. Therapy services may be provided only as reasonable and necessary for symptom control or to enable you to maintain activities of daily living and basic functional skills in accordance with the hospice philosophy. These services must be approved by the Hospice Interdisciplinary Group (IDG), and may not be appropriate for all hospice patients.

Hospice Aide/Homemaker: The hospice aide assists with the patient's personal care which includes bathing, hair care, shaving, skin care, linen changes, catheter care and straightening the patient's immediate surroundings. Hospice aides are not allowed to dispense medication.

The hospice aides at Carroll Hospice are Certified Nursing Assistants with home hospice experience. They will report any changes in the condition of the patient to the appropriate team member as well as the Hospice Clinical Manager. The frequency of hospice aides visits is determined by the nurse.

Volunteers: Hospice volunteers are carefully screened and specially trained to provide support and respite to the patients and families we serve. These dedicated people provide many different types of support for the Hospice patient and their family. Support can include running errands, preparing light meals and helping patients with their interests and hobbies. Volunteers can be a companion and friend and can also provide respite care to give the caregiver a break.

Volunteers are good listeners, non-judgmental, adaptable and have a strong desire to reach out with love and concern for others. The volunteer assigned will schedule visit times in coordination with your needs. If for any reason the volunteer cannot accommodate a specific requested time, you may contact the Volunteer Coordinator by calling **(410) 871-3000.**

Spiritual Counselor: Hospice spiritual care is based on high respect for the patient's and caregiver's personal faith and belief. The hospice spiritual counselor is available to assist patients and families cope with the significant spiritual issues that often arise during terminal illness. If you are not affiliated with a place of worship or connected with spiritual support, our hospice spiritual counselor will offer pastoral care visits and conduct your funeral or memorial service, if you desire. Our spiritual counselor will also contact your minister for additional support with your permission. The hospice spiritual counselor has received clinical training for this specialized form of ministry and will seek to provide spiritual support in a compassionate manner. Spiritual support services are available to all hospice patients and families who request such services. This request may be made at any time while the patient is receiving hospice services.

Dietary Counselor: Dietary counseling may be provided by a dietitian, nurse or other qualified staff member to address and ensure that your dietary needs are met.

Bereavement: Bereavement services are an integral part of the Hospice program. Following a terminal diagnosis, patients and families often struggle with anticipatory grief issues. The medical social worker and chaplain are available to assist families during this emotionally difficult time, as well as provide information on common aspects of anticipatory grief. Following a hospice patient's death, hospice continues to provide bereavement support to grieving families. All members of the family are eligible to receive bereavement services.

These services are available for a period of 13 months following the patient's death. They include regular mailings to provide support and education regarding grief issues, access to grief support groups, phone contacts and individual visits (as desired by the bereaved family) by the Bereavement Coordinator to assess bereavement coping skills and provide emotional support.

For needs that exceed the scope of hospice bereavement services, referrals to other organizations and professionals within the community are available. The grief support group is open to anyone in the three county area served by hospice.

MEDICARE HOSPICE BENEFITS

Medicare will reimburse the cost of hospice care under your Medicare Hospital Insurance (Part A). When all requirements are met Medicare will cover the following:

Services Covered Under the Medicare Hospice Benefit (if included in the plan of care): physician services, nursing care, medical appliances and supplies, medications for symptom management and pain relief of the terminal illness and related conditions (must be pre-approved by hospice), short-term inpatient care including respite care up to 5 days and pain and symptom control, hospice aide/homemaker, spiritual counseling, bereavement counseling, physical therapy, occupational therapy, speech therapy, medical social services, dietary and other counseling and volunteer services.

If you are receiving care under the Medicare Hospice Benefit, Medicare requires that no more than 30 days prior to the beginning of the third benefit period (180 days) and prior to each subsequent benefit period, a hospice physician or nurse practitioner must conduct a face-to-face visit with you to determine continued eligibility for hospice care. If you refuse to allow the face-to-face visit, you will no longer be eligible to receive hospice care under the Medicare Hospice Benefit.

If you have Medicare Part D coverage, we will work with your physician and pharmacy to determine which medications we will cover under the Medicare Hospice Benefit, which medications will be covered under your Part D plan and which medications are determined to be no longer medically necessary and if continued, would become your financial responsibility. If you disagree with any drug coverage determination, you may appeal the decision through the Medicare fee-for-service appeals process, Part D appeals process or submit a complaint with a Medicare-contracted Quality Improvement Organization (QIO). Please ask your hospice representative if you need assistance with any of these steps.

PLAN OF CARE

An individual Plan of Care will be developed for you by the Interdisciplinary Group of key professionals and other associates which is based upon identified problems, needs and goals, physician orders for medications, care, treatments and services, time frames, your environment and your personal wishes whenever possible.

The plan includes four basic areas:

- Physical care;
- Personal care and comfort;
- Spiritual needs; and
- Psychosocial needs.

The plan is continually reviewed and updated as needed, based on your changing needs. All medical information will be provided to assist you in participating in your Plan of Care. You must obtain pre-approval from the hospice for all treatments and services not included in the Hospice Plan of Care.

Medication and treatments are ordered by and given under the direction of your attending physician/hospice medical director. On admission, your hospice nurse will review with you what medications will be paid for by your insurance plan.

On admission, you and an agency representative will create a list of your current medications (including any over-the-counter medications, herbal remedies and vitamins). We will compare this list to the medications ordered by the physician. Our staff will continue to compare the list to the medications that are ordered, administered or dispensed to you while under our care. This will be done to resolve any discrepancies (such as omissions, duplications, contraindications, unclear information, potential interactions and changes).

MEDICAL RECORDS

Your medical record is maintained by our staff to document physician orders, assessments, progress notes and treatments. Your records are kept strictly confidential by our staff and are protected against loss, destruction, tampering or unauthorized use. Our Notice of Privacy Practices describes how your protected health information may be used by us or disclosed to others, as well as how you may have access to this information.

DISCHARGE, TRANSFER AND REFERRAL

Discharge, transfer or referral from hospice may result from several types of situations including the following:

- The level of care you need may alter sufficiently to warrant change;
- Situations may develop affecting your welfare or the safety of our associates;
- Failure to follow the attending physician's orders; and/or
- Failure to follow the Interdisciplinary Plan of Care.

You will be given timely advance notice of a transfer to another agency or discharge, except in case of emergency. If you are referred, transferred or discharged to another organization, we will provide them with a list of your current medications and information necessary for your continued care, including pain management.

Notice of Medicare Non-Coverage: You or your authorized representative will be asked to sign and date a Notice of Medicare Non-Coverage at least two days before your covered Medicare services will end. If you or your authorized representative are not available, we will make contact by phone, and then mail the notice. If you do not agree that your covered services should end, you must contact the Quality Improvement Organization (QIO) at the phone number listed on the form no later than noon of the day before your services are to end and ask for an immediate appeal.

EXPERIENCE OF CARE/PATIENT SATISFACTION SURVEYS

Our hospice has contracted with Deyta (HEALTHCAREfirst), a vendor approved by the Centers for Medicare and Medicaid Services (CMS) to perform mandatory Consumer Assessment of HealthCare Providers and Systems (CAHPS) surveys. The survey considers you and your primary caregiver as a unit of care. Our survey vendor, Deyta (HEALTHCAREfirst), may contact your caregiver or family member by mail or telephone after your death to evaluate the experience of care and services you and your loved ones received from our hospice agency.

Our patients are very important to us. Please ask questions if something is unclear regarding our services or the care you receive or fail to receive. Our hospice agency may also contact you, your caregiver or family at intervals to assess your satisfaction with the care and services we are providing. We will not ask the same questions included in the CAHPS survey. Your answers will help us to improve our services and ensure that we meet your needs and expectations.

NOTICE OF NONDISCRIMINATION/FILING A GRIEVANCE

Carroll Hospice proudly states that no person shall, on the grounds of race, creed, color, religion, sex, national/ethnic origin, ancestry, sexual preference, age, mental or physical handicap, social status, political beliefs or ability to pay, be excluded from participation in, be denied benefits of, or be subject to discrimination or harassment in the provision of any care or service.

Carroll Hospice provides aids and services, at no charge to the patient, and in a timely manner, for people with disabilities. Language assistance, including foreign language and sign language interpreter services, will also be provided in a timely manner and at no charge to the patient. If you or your loved one needs aids and services, contact your nurse case manager at (410) 871-8000.

If you believe that Carroll Hospice has failed to provide these services or has discriminated in another way, you may file a grievance in person or by mail, phone or fax using the contact information listed below. If you need help filing a grievance, please contact:

Regina Bodnar
Executive Director for Carroll Hospice
292 Stoner Ave, Westminster, MD 21157
Phone: (410) 871-8000
Fax: (410) 871-7242
TTY: (410) 871-7186

Carroll Hospice will not retaliate against any person who voices a concern about discrimination, who files a grievance related to discrimination or who participates in the investigation of a grievance related to discrimination.

You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, through an electronic portal, at https://ocrportal.hhs.gov/ocr/portal/lobby.jsf, by mail or by phone using the contact information below:

U.S. Department of Health and Human Services
200 Independence Avenue, SW
Room 509F, HHH Building
Washington, D.C. 20201
1-800-368-1019 (toll free) or 1-800-537-7697 (TDD)

Complaint forms are available at http://www.hhs.gov/ocr/office/file/index.html.

Grievances submitted to Carroll Hospice must be submitted within 60 days of the date that you become aware of the possible discriminatory action, and must state the problem and the solution sought. We will issue a written decision on the grievance no later than 30 days after its filing, including a notice of your right to pursue further administrative or legal action. You may file an appeal of our decision in writing to the Executive Director within 15 days. The Executive Director will issue a response within 30 days after its filing.

The availability and use of this grievance procedure does not prevent you from pursuing other legal or administrative remedies.

PROBLEM SOLVING PROCEDURE

We are committed to ensuring that your rights are protected. If you feel that our associates have failed to follow our policies or have in any way denied you your rights, please follow these steps without fear of discrimination or reprisal:

1. Discuss the problem with your Nurse Case Manager. Most problems can be resolved at this level.
2. Call the Clinical Manager at **(410) 871-8000.**
3. Call the Executive Director at **(410) 871-8000** and/or your family physician and describe the nature of your concern or grievance. Concerns and grievances presented to the Executive Director will be researched and resolved within 10 working days.
4. You may also contact the state's toll-free hotline at **1-800-492-6005 or (410) 402-8040**. The hotline is available for you to call 24 hours a day, 7 days a week. Normal business hours are 8:00 a.m. to 5:00 p.m., Monday through Friday (except holidays). If voicemail answers, please leave a message and your call will be returned. The purpose of the hotline is to receive complaints or questions about local home health/hospice agencies and to lodge complaints concerning the implementation of advance directive requirements. Written complaints may be submitted to:

   Office of Health Care Quality
   Spring Grove Hospital Center • Bland Bryant Building
   55 Wade Avenue, Catonsville, MD 21228

5. You may also lodge complaints with the Consumer Protection Division of the Attorney General's office 1-888-743-0023, the Commissioner of the State Department of Public Health or with any other person or agency.
6. You may also contact the Community Health Accreditation Partner (CHAP) hotline 24 hours a day at **1-800-656-9656**. Ask to speak to the Director of Quality.

SECTION III. Patient Rights and Responsibilities

Related to communication, decision making and advance directives

1. As a hospice patient you have the right to exercise your rights without discrimination or reprisal for doing so. A self-appointed or court-appointed representative may exercise these rights for you in the event that you are not capable of decision making. If you do not have an appointed representative, and you are not capable of decision making, Carroll Hospice will follow the State of Maryland's Health Care Decisions Act guidelines to determine who may make medical decisions on your behalf. You may also designate a legal representative at any time to exercise your rights and to make medical decisions on your behalf.
2. As a hospice patient you have the right to choose your hospice provider and, within the confines of the law, accept, refuse or discontinue any portion of planned treatment or services without relinquishing other portions of the treatment plan, except where medical contraindications to partial treatment exists; and to be given information concerning consequences of refusing all or partial treatment. You may do with without fear of reprisal or discrimination.
    a. You, or your representative on your behalf, can choose whether or not to participate in research, investigational or experimental studies or clinical trials.
3. You, or your representative on your behalf, have the responsibility to give accurate and complete health information to the best of your knowledge concerning present complaints, past illnesses, hospitalizations, medications, allergies and all other pertinent information.
4. You have the right to receive information in a manner you can understand and have access to interpreters as indicated and necessary to ensure accurate communication.
5. You have the right to formulate advance directives and receive written information about Carroll Hospice's policy and procedures on advance directives, including a description of applicable Maryland law. This information is available in this orientation booklet. Blank and sample documents are available from Carroll Hospice nurses and social workers, upon request.
    a. If advance directives have been previously completed, or are completed or amended during your hospice treatment, it is your responsibility to provide a copy of those documents to Carroll Hospice. Nursing and social work staff will assist you in arranging for copying, if needed.
    b. Carroll Hospice will follow the instructions provided in your advance directives or consult the person you designated for medical decision making when you are unable to make decisions on your behalf.
6. You, or your representative on your behalf, have the right and the responsibility to be involved in developing your hospice plan of care which addresses your unique health needs and to participate in updates and changes in the plan whenever necessary.
7. You, or your representative on your behalf, have the responsibility to ask questions or voice concerns when you do not understand something about your care, treatment, services or other instruction about what you are expected to do. If you cannot comply with the care plan, please inform Carroll Hospice staff.

Related to patient services and hospice plan of care and pain management

1. As a hospice patient you have the right to timely response from Carroll Hospice regarding any request for services.
2. You have the right to be informed in advance of care being provided about the services covered under the hospice benefit and the scope of services Carroll Hospice will provide including:
    a. Name(s) and responsibilities of staff members who are providing and responsible for your care, treatment or services
    b. Clear and understandable explanation of your medical problems, treatments and procedures to be provided
    c. Expected/unexpected outcomes or potential risks or problems
    d. Barriers to treatment
    e. How to contact the supervisor
    f. Service limitations
3. You have the right to choose your attending physician and other health care providers and communicate with those providers. Should your attending physician decline to participate in your hospice care, Carroll Hospice's Medical Director will be available to supervise your care or arrange for an alternate physician.
4. You have the right to receive pastoral and spiritual services. If you do not have services already in place and wish to have support services, Carroll Hospice will arrange for a hospice spiritual counselor (e.g., chaplain) or contact a clergy member of your particular faith to contact you to offer visits and support.
5. You, or your representative on your behalf, have the right to be informed about Carroll Hospice's discharge policy. This includes your right to revoke hospice services and to transfer your care to another hospice provider.
6. You have the right to receive effective pain management and symptom control from Carroll Hospice for conditions related to your terminal illness; and to receive education about your role and your caregiver's role in managing your pain when appropriate, as well as potential limitation and side effects of pain treatments.
7. You have the right to be informed of short-term inpatient care options available for pain control, management and respite.
8. You, or your representative on your behalf, have the responsibility to discuss your pain, pain relief options, and your questions, worries or concerns about pain medication with Carroll Hospice staff and appropriate medical personnel.

Regarding respect, voicing grievences and protection from mistreatment, discrimination and reprisal

1. Carroll Hospice proudly states that no person shall, on the grounds of race, creed, color, religion, sex, national/ethnic origin, ancestry, sexual preference, age, mental or physical handicap, social status, political beliefs or ability to pay, be excluded from participation in, be denied benefits of, or be subject to discrimination or harassment in the provision of any care or service.
   a. If you feel that you have been the victim of discrimination, you have the right to file a grievance without retaliation for doing so.
2. You have the right to have your person and property treated with courtesy and respect by all who provide hospice services to you. You have the right to unlimited contact with visitors and others of your choosing and to communicate privately with these persons.
3. You have a right to an environment that preserves your dignity and contributes to a positive self-image.
4. It is your responsibility (or that of your representative) to show respect and consideration for Carroll Hospice staff and equipment
5. You, or your representative on your behalf, have the right to voice grievances regarding treatment or care that is (or fails to be) furnished and the lack of respect for property by anyone who is furnishing services on behalf of Carroll Hospice without fear of coercion, discrimination, reprisal or an unreasonable interruption in care, treatment or services for doing so. Carroll Hospice must document both the existence of a complaint and the resolution of the complaint. Our complaint resolution process is explained in our Patient Orientation booklet. When accepted for treatment or care, be advised of the availability of the state's toll-free home care hotline number, its purpose and hours of operation. The hotline receives complaints or questions about local hospice agencies and is also used to lodge complaints concerning the implementation of the advance directives requirements. Hotline hours are 8:30 a.m. to 5:00 p.m., Monday through Friday.
   a. The state hotline may be reached at 1-800-492-6005.
   b. You may also call the CHAP hotline 24 hours a day at 1-800-656-9656.
6. You have the right to be free from mistreatment, abuse, neglect, verbal, mental, sexual and physical abuse, injuries of unknown source and misappropriation of your property. All mistreatment, abuse, neglect, injury and exploitation complaints by anyone furnishing service on behalf of Carroll Hospice are reported immediately by our staff to Carroll Hospice's Executive Director (or designee). All reports will be promptly investigated and immediate action taken to prevent potential violations during our investigation. Carroll Hospice will take appropriate corrective action in accordance with Maryland law. All verified violations will be reported to the appropriate Maryland and Carroll County authorities including state survey and certification agencies within 5 working days of becoming aware of the violation.
7. It is your responsibility to follow Carroll Hospice's rules and regulations.

Regarding privacy and confidentiality

1. You have the right to confidentiality of written, verbal and electronic information including your medical records, information about your health, social and financial circumstances or about what takes place in your home.
    a. You, or your representative on your behalf, have the right to consent, refuse or revoke consent for filming or recording of care, treatment and services for purposes other than identification, diagnosis and treatment.
2. You, or your representative on your behalf, have the right to request that Carroll Hospice release information written about you only as required by law or your written authorization and to be advised of our policies and procedures regarding clinical records.
    a. You, or your representative on your behalf, have the right to access, request changes to and receive an accounting of disclosures regarding your health information as permitted by law.

Regarding payment for services and agency ownership

1. You have the right to be advised verbally, in writing and before care is initiated, of our billing policies and payment procedures and the extent to which payment may be expected from Medicare, Medicaid, any other federally funded or aided program or any other sources known to us. This includes information about charges for services that will not be covered by these programs or your health insurance and charges that you may have to pay.
    a. If changes in payment, charges or patient payment liability occur, Carroll Hospice will advise you of these changes as soon as possible, but no later than 30 calendar days from the date Carroll Hospice is notified of the change.
2. You have the right to receive upon your request or that of your representative, Carroll Hospice's policy on uncompensated care.
3. You, or your representative on your behalf, have the right to receive a fully itemized billing statement, upon request.
4. You, or your representative on your behalf, have the responsibility to promptly meet your financial obligations and responsibilities agreed upon with Carroll Hospice. This includes cooperation with Carroll Hospice staff that will assist you in applying for available benefits that may help you meet these financial obligations and responsibilities.
5. You have the right to receive information about Carroll Hospice's ownership and control.
6. You have the right to receive information addressing any beneficial relationship between Carroll Hospice and referring agencies.

In addition to all other rights as a hospice, the patient residing in a hospice house has the right to:

1. Privacy, including the right to have a staff member knock on the resident's door before entering.
2. Be free from mental, verbal, sexual and physical abuse, neglect, involuntary seclusion and exploitation.
3. Be free from physical and chemical restraints.
4. Manage personal financial affairs.
5. Maintain legal council.
6. Attend or not attend religious services as the patient chooses and receive visits from members of the clergy.
7. Possess and use personal clothing and other personal effects to a reasonable extent, and to have reasonable security for those effects in accordance with the hospice house's security policy.
8. Meet or visit privately with any individual the patient chooses in accordance with patient and facility safety.
9. Have reasonable access to the private use of a telephone within the facility.
10. Retain personal clothing and possessions as space permits with the understanding that the hospice house may limit the number of personal possessions retained at the facility for the health and safety of other patients.

Notice of Patient Rights - The hospice house shall place a copy of the patient's rights a set forth in this regulation, in a conspicuous location, plainly visible and easily read by patients, staff and visitors, and provide a copy to each patient and patient's representative on admission.

Patient Responsibilities:

1. Give accurate and complete health information to the best of your knowledge concerning your present complaints, past illnesses, hospitalization medications, allergies and all pertinent information.
2. Assist in developing and maintaining a courteous and safe environment (such as keeping pets confined, not smoking or putting weapons away during your care).
3. Inform Carroll Hospice in a timely manner when you will not be able to keep a scheduled home health care visit and any changes in status, (i.e., phone, address or hospitalization).
4. Participate in the development of your home health care plan and adhere to your developed plan.
5. Ask questions when you do not understand about your care, treatment and service or other instruction about what you are expected to do. If you have concerns about your care or cannot comply with the plan, let us know.
6. Voice concerns or problems to a hospice representative and request further information concerning anything you do not understand.
7. Discuss pain, pain relief options and your questions, worries and concerns about pain medication with staff or appropriate medical personnel.
8. Promptly meet your financial obligations and responsibilities agreed upon with the agency.
9. Follow the organization's rules and regulations.
10. Show respect and consideration for agency staff and equipment.

NOTICE OF PRIVACY PRACTICES

Effective Date: November 1, 2015

THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED, AND HOW YOU CAN GET ACCESS TO THIS INFORMATION. PLEASE REVIEW IT CAREFULLY.

WHO WILL FOLLOW THIS NOTICE:

This notice describes our Agency's practices and that of:

- Any health care professional authorized to enter information into your hospice chart.
- Any member of a volunteer group we allow to help you while you are a patient.
- All employees of Carroll Hospice (CH) staff in all departments and units.

Carroll Hospice, Inc., Carroll Hospital, and members of the medical staff of the hospital and its LifeBridge Health affiliates may share medical information with each other for treatment, payment or health care operations purposes described in this notice.

OUR PLEDGE REGARDING MEDICAL INFORMATION:

We understand that your medical information is personal and we are committed to protecting that information. We create a record of the care you receive at CH. We need this record to provide you with quality care and to comply with certain legal requirements. This notice applies to all of the records of your care generated by CH, whether made by CH personnel or your personal doctor. Your personal doctor may have different policies or notices regarding the doctor's use and disclosure of your medical information created in the doctor's office or clinic.

This notice will tell you about the ways we may use and disclose your medical information as well as explain what your rights and obligations are regarding the use and disclosure of the information. We are required by law to:

- Make sure that medical information that identifies you is kept private.
- Give you this notice of our legal duties and privacy practices with respect to medical information about you.
- Follow the terms of the notice that is currently in effect.

HOW WE MAY USE AND DISCLOSE MEDICAL INFORMATION ABOUT YOU WITHOUT WRITTEN CONSENT:

The following categories describe different ways that we use and disclose medical information. For each category we will explain what we mean and try to give an example. Not every use or disclosure in a category will be listed. However, all of the ways we are permitted to use and disclose information will fall within one of the categories.

For Treatment. We may record in your medical record medical information about you and we may use this medical information to provide you with medical treatment or services. We may disclose medical information about you to doctors, nurses, technicians, medical students or other CH personnel who are involved in taking care of you at CH.

This information is necessary for these health care providers to determine what medical treatment you should receive. Different departments of CH also may share medical information about you in order to coordinate the different things you need, such as prescriptions, lab work and X-rays. We also may disclose medical information about you to people outside CH who may be involved in your medical care after you leave CH, such as other medical providers who will provide services that are part of your care.

For Payment. For scheduled procedures or treatments that require prior approval, we may contact your insurer to determine if your plan will cover the cost of the procedure or treatment. For example, we may need to give your health plan information about your care plan/treatments to obtain prior approval or to determine whether your plan will cover costs.

For Health Care Operations. We may use and disclose medical information about you for CH operations. These uses and disclosures are necessary to run CH and make sure that all of our patients receive quality care. For example, we may use medical information about you to evaluate our staff and services or for teaching purposes. We may also combine medical information about CH patients with info from other hospices to see where we can make improvements in the quality of care and services we offer.

Appointment Reminders. We may use and disclose medical information to contact you as a reminder that you have an appointment for treatment or medical care at the CH and to communicate necessary information about your appointment.

Treatment Alternatives and Health-Related Services. We may use and disclose medical information to tell you about, or recommend, possible treatment options, alternatives, health-related benefits or services that may be of interest to you.

Fundraising Activities. We may use information about you or disclose it to our Foundation office so they may contact you in an effort to raise money for the CH and its operations. We only would release demographic information (such as your name, address and phone number, date of birth, gender), department of service, treating physician(s) and the dates you received treatment or services. If you do not want to be contacted for fundraising efforts or if you have previously opted out of the fundraising mailings and wish to opt back in, you must notify the Foundation Office, Carroll Hospital, 200 Memorial Avenue, Westminster, MD 21157 in writing, via email at Foundation@carrollhospitalcenter.org, or by telephone at 410-871-6200.

Individuals Involved in Your Care or Payment for Your Care. Unless you object, we may release medical information about you to a friend or family member who is involved in your medical care. We may also give information to someone who helps pay for your care. In addition, we may disclose medical information about you to an entity assisting in disaster relief efforts so that your family can be notified about your condition, status and location.

Workers' Compensation. We may release medical information about you for workers' compensation or similar programs following written request by your employer, worker's compensation insurer or their representative. These programs provide benefits for work-related injuries or illness.

Organ and Tissue Donation. We will disclose medical information to organizations that obtain, bank or transplant organs and tissues.

Coroners, Medical Examiners and Funeral Directors. We may release medical information about you to a coroner or medical examiner. This may be necessary, for example, to identify a deceased person or determine the cause of death. We may also release medical information about patients of CH to funeral directors as necessary to carry out their duties.

Research. Under certain circumstances, we may use and disclose medical information about you for research purposes or to people conducting a research proposal; for example, a research project may involve comparing the health and recovery of all patients who received one medication to those who received another, for the same condition. All research projects, however, are subject to a special approval process through our Institutional Review Board that has reviewed the research proposal to ensure the privacy of your medical information. We may also disclose medical information about you to people conducting a research project; for example, to help them look for patients with specific medical needs, so long as the medical information they review does not leave CH.

Public Health Risks. We may disclose medical information about you for public health activities. These activities generally include the following:

- To prevent or control disease, injury or disability.
- To report deaths.
- To report possible child abuse or neglect or vulnerable adult abuse or neglect.
- To report reactions to medications or problems with products to the Food and Drug Administration.
- To notify people of recalls of products they may be using or have used while at CH.
- To notify a person who may have been exposed to a disease or may be at risk for contracting or spreading a disease or condition; usually upon direction of the state or county health department.

Health Oversight Activities. We may disclose medical information to a health oversight agency for activities authorized by law. These oversight activities include audits, investigations, inspections and licensure.

To Avert a Serious Threat to Health or Safety. We may use and disclose medical information about you when necessary to prevent a serious threat to the health and safety of you or another person. Any disclosure, however, would only be to someone able to help prevent the threat.

As Required by Law. We will disclose medical information about you when required or permitted to do so by federal, state or local law.

Lawsuits and Disputes. We may disclose your medical information in the course of any judicial or administrative proceeding or in response to an order of a court or administrative tribunal (to the extent such disclosure is expressly authorized). If certain conditions are met, we may also disclose your medical information in response to a subpoena, a discovery request, or other lawful process.

Law Enforcement. We may release medical information about you if asked to do so by a law enforcement official:

- In response to a court order, subpoena, warrant, summons or similar process.
- To identify or locate a suspect, fugitive, material witness or missing person.
- About a death we believe may be the result of criminal conduct.
- About criminal conduct at CH.
- In emergency circumstances to report a crime; the location of the crime or victims; or the identity, description or location of the person who committed the crime.
- To report suspicious wounds, burns, or other physical injuries.

Military and Veterans. If you are a member of the Armed Forces, we may release medical information about you as required by military command authorities. We may also release medical information about foreign military personnel to the appropriate foreign military authority.

National Security, Intelligence Activities and Protective Services. We may release medical information about you to authorized federal officials for intelligence, counterintelligence and other national security activities authorized by law and for protective services for certain public and foreign officials.

Inmates. We may release medical information about an inmate of a correctional institution or individual in the custody of a law enforcement official to that correctional institution or law enforcement official. This release would be necessary (1) for the institution to provide you with health care; (2) to protect the health and safety of you or other inmates; or (3) for the safety and security of the correctional institution.

To, From and Between Business Associates. CH contracts with business associates to provide certain services. We may release medical information about you to our business associates, receive medical information about you from our business associates, and our business associates may share medical information about you between themselves.

For example, we may disclose medical information about you to a third-party service provider responsible for billing or providing other services to us. To protect your medical information, however, CH requires business associates to sign contracts agreeing to appropriately safeguard such information.

To DHHS. We may disclose your medical information in response to investigations by the Department of Health and Human Services.

Health Information Exchanges. We may participate in health information exchanges to facilitate the secure exchange of your electronic health information between and among several health care providers or other health care entities for your treatment, payment or other health care operations purposes. This means we may share information we obtain or create about you with outside entities (such as hospitals, doctors' offices, pharmacies or insurance companies) or we may receive information they create or obtain about you (such as medication history, medical history or insurance information) so each of us can provide better treatment and coordination of your health care services.

OTHER USES OF MEDICAL INFORMATION

Most use and disclosures of psychotherapy notes, use and disclosures of PHI for marketing purposes, and disclosures that constitute the sale of PHI requires your written authorization. Other uses and disclosures of medical information not covered by this notice or the laws that apply to us will be made only with your written permission. If you provide us permission to use or disclose medical information about you, you may revoke that permission, in writing, at any time. If you revoke your permission, we will no longer use or disclose medical information about you for the reasons covered by your written authorization, except to the extent that action has already been taken by the CH.

YOUR RIGHTS REGARDING MEDICAL INFORMATION ABOUT YOU

You have the following rights regarding medical information we maintain about you:

Right to Inspect and Copy. You have the right to inspect and copy most of your medical information that may be used to make decisions about your care as provided for in the Code of Federal Regulations (C.F.R.), for as long as we maintain it as required by law. Usually, this includes medical and billing records, but does not include psychotherapy notes.

To inspect and copy medical information that may be used to make decisions about you, you must submit your request in writing to Carroll Hospice, Performance Improvement Department, 292 Stoner Avenue, Westminster, MD 21157. To the extent we use or maintain this information in an electronic health record, you may request that we provide you with a copy of such information in electronic form you desire, if that information is readily producible in such form or format. If you request a copy of the information, we may charge a nominal fee for the costs of copying, mailing or other supplies associated with your request.

We may deny your request to inspect and copy in certain, very limited circumstances. If you are denied access to medical information, you may request that the denial be reviewed. Another licensed health care professional chosen from Carroll Hospice (CH) will review your request and the denial. The person conducting the review will not be the person who denied your request. We will comply with the outcome of the review.

Right to Amend. If you feel that medical information we have about you is incorrect or incomplete, you may ask us to amend the information as provided in the Code of Federal Regulations (C.F.R.). You have the right to request an amendment for as long as the information is kept by CH.

To request an amendment, your request must be made in writing and submitted to the address below. You must provide a reason that supports your request. We may deny your request for an amendment if it is not in writing or does not include a reason to support the request.

In addition, we may deny your request if you ask us to amend information that:

- Was not created by us, unless the person or entity that created the information is no longer available to make the amendment.
- Is not part of the medical information kept by or for CH.
- Is not part of the information which you would be permitted to inspect and copy.
- Is believed accurate and complete by the documenter.

We will distribute your request (or a summary) with all future disclosures of information to which it relates, but only if you ask us to do so. Further, you may submit a written statement disagreeing with the denial and we will keep it on file and distribute it (or a summary) with all future disclosures of the information to which it relates.

Right to an Accounting of Disclosures. You have the right to request an "accounting of disclosures." This is a list of certain disclosures we made of medical information about you, but does not include disclosures:

- To you or to persons involved in your health care or payment for that care.
- Pursuant to your written authorization.
- For the purpose of carrying out treatment, payment or health care operations.
- That are incidental to another permissible use or disclosure.
- For disaster relief, national security or intelligence purposes.
- To correctional institutions or law enforcement officers who have you in custody at the time of the disclosure.
- As part of a limited data set.
- To a health oversight agency or law enforcement official if they so request

To request this information, you must submit your request in writing to the address below. Your request must state a time period which may not be longer than six years. Your request should indicate in what form you want the accounting (for example, on paper or electronically). The first accounting you request within a 12-month period will be free. For additional accountings, we may charge you for the costs of providing the accounting. We will notify you of the cost involved and you may choose to withdraw or modify your request at that time before any costs are incurred.

Right to Request Restrictions. You have the right to request a restriction or limitation on the medical information we use or disclose about you for treatment, payment, or health care operations as provided in the Code of Federal Regulations (C.F.R.). You also have the right to request a limit on the medical information we disclose about you to someone who is involved in your care or the payment for your care, like a family member or friend. For example, you could ask that we not use or disclose information about a treatment you had.

We are not required to agree to your request. If we do agree, we will comply with your request unless the information is needed to provide you emergency treatment.

To request restrictions, you must make your request in writing to Carroll Hospice, Performance Improvement Department, 292 Stoner Avenue, Westminster, MD 21157. In your request, you must tell us (1) what information you want to limit; (2) whether you want to limit our use, disclosure or both; and (3) to whom you want the limits to apply, for example, disclosures to your spouse.

We reserve the right to terminate any previously agreed to restrictions (other than a restriction we are required to agree to by law). We will inform you of the termination of the agreed-to restriction and such termination will only be effective with respect to medical information created after we inform you of the termination.

If we are required to grant your request, or if we agree to do so, we will comply with your request unless the information is needed to provide you emergency treatment.

Right to Request Confidential Communications. You have the right to request that we communicate with you about medical matters in a certain way or at a certain location as provided in the Code of Federal Regulations (C.F.R.). For example, you can ask that we only contact you at work or by mail.

To request confidential communications, you must make your request in writing to the address below. We will not ask you the reason for your request. We will accommodate all reasonable requests. Your request must specify how or where you wish to be contacted.

Right to be Notified of a Breach. You have the right to be notified in the event that we (or one of our Business Associates) discovers a breach involving your medical information.

Right to a Paper Copy of This Notice. You have the right to a paper copy of this notice. You may ask us to give you a copy of this notice at any time. You may print this document off of our website, download the corresponding PDF of our Privacy Notice/HIPAA brochure or contact the Performance Improvement Department, 292 Stoner Avenue, Westminster, MD 21157 to receive a copy mailed to your home.

Even if you have agreed to receive this notice electronically, you are still entitled to a paper copy of this notice.

CHANGES TO THIS NOTICE: We reserve the right to change this notice. We reserve the right to make the revised or changed notice effective for medical information we already have about you as well as any information we receive in the future. We will post a copy of the current notice in CH. The notice contains, on the first page, the effective date. In addition, each time you register at or are admitted by CH for treatment or health care services as a patient, we will offer you a copy of the current notice in effect.

COMPLAINTS AND CONTACT INFORMATION: If you have any questions about this notice or wish to request further information, contact the Privacy Officer listed below.

If you believe your privacy rights have been violated, you may file a complaint with CH or with the Secretary of the Department of Health and Human Services U.S. Department of Health & Human Services, 200 Independence Avenue, S.W., Washington, D.C. 20201. To file a complaint with CH, contact the Performance Improvement Department at the address listed below. All complaints must be submitted in writing. You will not be retaliated against for filing a complaint.

Performance Improvement Department
Carroll Hospice
292 Stoner Avenue
Westminster, MD 21157
Telephone: (410) 871-8000

SECTION IV. Advance Directives

It is your right to decide about the medical care you will receive. You have the right to be informed of treatment options available before giving consent for medical treatment. You also have the right to accept, refuse or discontinue any treatment at any time.

All of us who provide you with health care services are responsible for following your wishes; however, there may be times when you may not be able to decide or make your wishes known. Many people want to decide ahead of time what kinds of treatment they want to keep them alive. The Advance Directive states your choice about treatment and may name someone to make treatment choices if you cannot.

Maryland law recognizes two ways of making health care decisions for the future, including decisions about treatments used to sustain life. These two ways are written and oral Advance Directives. The written Advance Directive has the following two parts:

- Health Care Instructions
- Appointment of a Health Care Agent

Health Care Instructions (Maryland's living will) is a legal document that lets you state your wishes about medical care in the event that you can no longer make your own medical decisions. If you wish to refuse life-sustaining treatment, it may be withheld or withdrawn only after your doctor and one other doctor certify that you are in a terminal condition, have an end-stage condition or are in a permanent vegetative state. It becomes effective when your doctor certifies in writing that you are incapable of making an informed decision, but are not unconscious or unable to communicate by any means and one other doctor must agree with your attending physician's opinion.

An Appointment of Health Care Agent is a legal document which allows you to designate a particular person to make decisions regarding your medical care, including life support, when you are not able to do so. Choose your health care agent carefully and make sure he or she knows what you want. This person should be someone you trust to carry out your wishes. This person cannot be an owner, operator or employee of your treating health care facility unless he/she is a relative, spouse or close friend. You can also appoint a second person as your alternate agent.

You do not need to notarize your Advance Directives. However, both of these documents must be signed by two witnesses. Witnesses may not be the person you named as your agent, and at least one of the witnesses cannot be a person who is entitled to any part of your estate and who is not entitled to any financial benefit by reason of your death. You should give a copy of your Advance Directive to your doctor, family or friends and health care providers. Keep the originals with other important papers in a safe place that is easy to find.

Your Advance Directive can be canceled or changed at any time. If you decide to cancel your Advance Directive, you may do so by issuing a signed and dated written revocation (cancellation); destroying or defacing your document; orally informing your doctor of your revocation or by making another Advance Directive. Make sure you notify anyone who has a copy of your original Advance Directive that you have canceled it. **Please inform us if you execute or change either of these documents during the course of your care.**

Maryland law also lets you make an **Oral Advance Directive** to your doctor. An oral advance directive is legally effective and should be honored by your health care providers. You must communicate your decision to your doctor in front of a witness and your decision must be written in your medical record at the time it is made and signed by the witness. You should look at what is written down to make sure it reflects your wishes.

If you executed an Advance Directive before July 1, 1991, you may want to review it, since a new law has gone into effect which gives you more options and information. Even if you decide not to update it, the old documents are still legal.

Effective July 1, 2013, Maryland's advance directive law requires a Medical Orders for Life-Sustaining Treatment (MOLST) form to be completed if you are admitted to a nursing home, assisted living facility, hospice, home health agency or dialysis center. You will be offered an opportunity to participate in completing the MOLST form, outlining your wishes for cardiopulmonary resuscitation and other life-sustaining treatments during the admission process. If you already have a MOLST form on file from a previous admission, you may ask to update your wishes by voiding the existing form and completing a new one. You will be provided a copy of the completed form within 48 hours or sooner, if being discharged or transferred. If you decline to complete and/or update a MOLST form, your health care provider will document this in your medical record. Your health care agent or surrogate decision maker may complete or update a MOLST form on your behalf if you are not competent to do so.

The MOLST form must be signed and dated by a physician or nurse practitioner in order to be valid. It is a portable document, moving with you across any health care setting, increasing the likelihood that your wishes regarding life-sustaining treatment are honored throughout the health care system.

We must document in your medical record whether or not you have executed an Advance Directive. **We will abide by your advance directives.** Care will be provided to you regardless of whether or not you have executed an Advance Directive. It is our policy to honor advance directives to the extent permitted by law and to support a patient's right to actively participate in making health care decisions.

If you would like more information, or a copy of Advance Directive forms, write to or call:

Maryland Attorney General's Office
200 St. Paul Place, Baltimore, MD 21202
Phone: (410) 576-7000

AGENCY POLICY ON ADVANCE DIRECTIVES

Our agency complies with the Patient Self-Determination Act of 1990, which requires us to:

- Provide you with written information describing your rights to make decisions about your medical care;
- Document advance directives prominently in your medical record and inform all staff;
- Comply with requirements of state law and court decisions with respect to advance directives; and
- Provide care to you regardless of whether or not you have executed an advance directive.

We must document in your medical record whether or not you have executed an Advance Directive. **We will abide by your advance directives.** Care will be provided to you regardless of whether or not you have executed an Advance Directive. It is our policy to honor Advance Directives to the extent permitted by law and to support a patient's right to actively participate in making health care decisions.

An ethics committee is available to serve in an advisory capacity when ethical issues, such as the withdrawal or withholding of life-sustaining treatments arise during the care of patients with or without an advance directive. Discussion shall involve the patient and/or designated representatives, the home care staff involved in the patient's care and the patient's physician.

Unless the physician has written a specific **Do Not Resuscitate (DNR)** order, it is our policy that every patient will receive cardiopulmonary resuscitation (CPR). If you do not wish to be resuscitated, you, your family or your Appointed Health Care Agent must request DNR orders from your physician. These orders are documented in your medical record and routinely reviewed; however, **you may revoke your consent to such an order at any time.**

If you would like more information, or a copy of Advance Directive forms, write to or call: Maryland Attorney General's Office, 200 St. Paul Place; Baltimore, MD 21202; Phone: (410) 576-7000.

SECTION V. Emergency Preparedness

In the event of a natural disaster, inclement weather or emergency, we have an emergency operations plan to continue necessary patient services. We will make every effort to continue home care visits; however, the safety of our staff must be considered. When roads are too dangerous to travel, our staff will contact you by phone, if possible, to let you know that they are unable to make your visit that day. Every possible effort will be made to ensure that your medical needs are met.

All patients are assigned a priority level code that is updated as needed. The code assignment determines agency response priority in case of a disaster or emergency. These codes are maintained in the agency office, along with information which may be helpful to Emergency Management Services in case of an area disaster or emergency. You will be contacted for medical attention:

☐ **Level I** - Within 24 hours
☐ **Level II** - Within 24-48 hours
☐ **Level III** - Within 48-72 hours

In case of bad weather or other situations that might prevent our staff from reaching you, turn to your local radio and/or TV station(s). Please notify our office if you evacuate to another location or emergency shelter.

POWER OUTAGE

If you need help in a power outage and our phone lines are down:

- Call 911 or go to the emergency room if you have an emergency.
- Call your closest relative or neighbor if it is not an emergency.

LIGHTNING

If you are inside:

- Avoid tubs, faucets and sinks because metal pipes conduct electricity.
- Stay away from windows.
- Avoid using phones with cords except for emergencies.

If you are outside:

- Avoid natural lightning rods such as tall trees in open areas.
- Get away from anything metal.

FLOOD

Be aware of flood hazards, especially if you live in a low-lying area, near water or downstream from a dam. Flooding can take days to happen, but flash floods produce raging waters in minutes. Six inches of moving water can knock you off your feet. Avoid moving water if you must walk in a flooded area. Use a stick to test if the ground is firm enough to walk on.

Be ready to evacuate if a flood watch is issued. Move important items upstairs. Fill a clean bathtub with water in case water becomes contaminated or is shut off. Turn off your utilities at the main valves if you are instructed to do so. Do not touch electrical equipment if you are wet or standing in water.

TORNADO

As soon as a tornado is sighted, go to the lowest floor and find an interior room. Good shelters are basements, rooms and halls with no outside walls, bathtubs and spaces under the stairs. Many public buildings have designated shelter areas. Stay away from windows, doors and outside walls. Get under a sturdy item, such as a table, and protect your head. Stay until the danger passes.

If the patient is bedbound, move the bed as far from windows as you can. Use heavy blankets or pillows to protect the head and face.

If you are in a vehicle, trailer or mobile home, get out immediately and go to a sturdy structure. If there is not one close by, lie flat in the nearest ditch and cover your head. Do not try to out-drive a tornado. They are erratic and move swiftly.

WINTER STORM

Heavy snowfall and extreme cold can immobilize a region, resulting in isolation. Icy and/or blocked roads and downed power lines can happen any time it is cold or snowy. Wear layers of loose, lightweight, warm clothes, rather than one heavy layer. Wear hats and outer layers that are tightly woven and water repellent. Mittens will keep your hands warmer than gloves.

EMERGENCY KIT FOR THE HOME

Bad weather can be dangerous, so be prepared. Keep a kit with these items in case you have a weather emergency:

- Battery-powered radio
- Lamps and flashlights
- Extra batteries
- Food that you do not have to cook
- Manual can opener
- Utensils, cups and plates
- Medications
- Extra blankets
- Water in clean milk or soda bottles
- Rock salt or sand for walkways
- Extra fuel

SHELTER SUPPLIES

The following is a list of what to bring to a shelter during an evacuation:

- Two-week supply of medications
- Medical supplies and oxygen
- Wheelchair, walker, cane, etc.
- Special dietary foods/can opener
- Air mattress/cot and bedding
- Lightweight folding chair
- Extra clothing, hygiene items, glasses
- Important papers
- Valid ID with current name and address
- Hospice folder

Most shelters have electric power from a generator. If you evacuate to a shelter, bring your electrical devices (such as an oxygen concentrator).

NOTE: Pets are not usually allowed in shelters.

EMERGENCY PREPAREDNESS AND PETS

When disaster strikes, the same rules that apply to people apply to pets - if it is not safe for you, it is not safe for them. Planning ahead can make all the difference in whether your pet will survive a disaster.

- **ID your pet:** Consider having your pet micro-chipped. Make sure your pet is wearing a securely-fastened collar with up-to-date identification. Put your cell phone number on your pet's tag. Birds should be caged with identification attached to the cage.
- **Put together a disaster kit for your pet:** Food and water for at least five days for each pet; bowls, manual can opener, medications and medical records, including vaccination schedules; leashes, harnesses and carriers; cat litter box, litter and scoop; paper towels and garbage bags to collect your pet's waste; current photos of you with your pets to help others identify them in case you and your pets become separated, written information about feeding schedules, medical conditions and behavior issues. Plan to take your pets with you in an evacuation. If it is not safe for you to stay, it is not safe for them either.
- **Find a pet-friendly refuge ahead of time:** With the exception of service animals, pets usually are not allowed in public shelters. Make sure you know the hotels that will accept you and your pets in an emergency, and prepare a list with phone numbers. Call ahead for reservations if you know you may need to evacuate. Ask if no-pet policies could be waived in an emergency. Identify friends, boarding facilities, animal shelters or veterinarians that can care for your animals in an emergency. Although your animals may be more comfortable together, be prepared to house them separately.

SECTION VI. Home Safety

All patients need to take special precautions to ensure a safe living environment. Most accidents in the home can be prevented by eliminating hazards. This list will help you find potential hazards in your home. Take note of each statement that you need to work on to make your home a safer place. **Please speak with your nurse/therapist or call the agency at any time if you have any concerns or questions about patient safety.**

PREVENTING FALLS

At least half of all falls happen at home. Each year, thousands of older Americans experience falls that result in serious injuries, disability and even death. Falls are often due to hazards that are easily overlooked but easy to fix. Use the following **SELF ASSESSMENT**. Check all of the risk factors below that apply to you and your home. The more factors checked, the higher your risk for falling.

☐ **History of Falling** - 2 or more falls in last 6 months.
☐ **Vision Loss** - changes in ability to detect and discriminate objects; decline in depth perception; decreased ability to recover from a sudden bright light or glare.
☐ **Hearing Loss** - may not be as quickly aware of a potentially hazardous situation.
☐ **Foot Pain/Shoe Problems** - foot pain; decreased sensation/feeling; skin breakdown; ill-fitting or badly worn footwear.
☐ **Medications** - taking four or more medications; single or multiple medications that may cause drowsiness, dizziness or low blood pressure.
☐ **Balance and Gait Problems** - decline in balance; decline in speed of walking; weakness of lower extremities.
☐ **High or Low Blood Pressure** that causes unsteadiness.
☐ **Hazards Inside Your Home** - tripping and slipping hazards; poor lighting; bathroom safety; spills; stairs; reaching; pets that get under foot.
☐ **Hazards Outside Your Home** - uneven walkways; poor lighting; gravel or debris on sidewalks; no handrails; pets that get under foot; hazardous materials (snow, ice, water, oil) that need periodic removal and clean up.

Review each of the following safety tips and note the ones you need to work on:

- Keep emergency numbers in large print near each phone.
- Put a phone near the floor in case you fall and can not get up.
- Wear shoes that give good support and have thin, non-slip soles. Avoid wearing slippers and athletic shoes with deep treads.
- Remove things you can trip over (such as papers, books, clothes and shoes) from stairs and places where you walk.
- Keep outside walks and steps clear of snow and ice in the winter.
- Remove small throw rugs or use double-sided tape to keep them from slipping.
- Ask someone to move any furniture so your path around the house is clear.

- Clean up spills immediately.
- Be aware of where your pets are at all times.
- Do not walk over or around cords or wires, i.e., cords from lamps, extension cords, or telephone cords. Coil or tape cords and wires next to the wall so you can not trip over them. Have an electrician add more outlets if needed.
- Keep items used often within easy reach (about waist high) in cabinets.
- Use a steady step stool with a hand bar. Never use a chair as a step stool.
- Improve the lighting in your home. Replace bulbs as needed. Lamp shades or frosted bulbs can reduce glare.
- Make sure stairways, halls, entrances and outside steps are well lit. Have a light switch at the top and bottom of the stairs.
- Place a lamp, flashlight and extra batteries within easy reach of your bed.
- Place night lights in bathrooms, halls and passageways so you can see at night.
- Make sure the carpet is firmly attached to every step. If not, remove the carpet and attach non-slip rubber treads on the stairs. Paint a contrasting color on the top front edge of all steps so you can see the stairs better.
- Fix loose handrails or put in new ones. Make sure handrails are on both sides of the stairs and are as long as the stairs. Fix loose or uneven steps.
- Install grab bars next to your toilet and in the tub or shower.
- Use non-slip mats in the bathtub and on shower floors.
- Use an elevated toilet seat and/or shower stool, if needed.
- Exercise regularly. Exercise makes you stronger and improves your balance and coordination. Talk to your doctor about what exercise is right for you
- Have your nurse, doctor or pharmacist look at all the medicines you take, even over-the-counter medicines. Some medicines can make you sleepy or dizzy.
- Have your vision checked at least once a year by an eye doctor. Poor vision can increase your risk of falling.
- Get up slowly after you sit or lie down.
- Use a cane or assistive device for extra stability, if needed.
- Consider wearing a device that brings help if you fall and can not get up.

FIRE SAFETY/BURN PRECAUTIONS

- Make sure the patient has easy access to a telephone, and post the fire department number on every telephone. All family members and caregivers should be familiar with emergency 911 procedures.
- Notify the fire department if a disabled person is in the home.
- **Do not smoke (including e-cigarettes) in bed or where oxygen is being used.** Never leave burning cigarettes unattended. Do not empty smoldering ashes in a trash can. Keep ashtrays away from upholstered furniture and curtains.

- Install smoke detectors on every floor of your home, including the basement. Place smoke detectors near rooms where people sleep. Test smoke detectors every month to make sure they are working properly.
- Install new smoke detector batteries twice a year or when you change your clocks in the spring and fall.
- Fire extinguishers should be checked frequently for stability.
- Make a family fire escape plan and practice it every six months. Plan at least two different escape routes from each room for each family member. If your exit is through a ground floor window, make sure it opens easily.
- If you live in an apartment building, know where the exit stairs are located. Do not use an elevator during a fire emergency.
- Designate a safe place in front of the house or apartment building for family members to meet after escaping a fire.
- If your fire escape is cut off, remain calm, close the door and seal cracks to hold back smoke. Signal for help at the window.
- Evacuate a bedbound patient to a safe area by placing him or her on a sturdy blanket and pulling or dragging the patient out of the home.
- Avoid excess clutter of newspapers, magazines, clothing, etc. These piles can become a fuel source for potential fires.
- Remember, life safety is first, but if the fire is contained and small, you may be able to use your fire extinguisher until the fire department arrives.
- Have your heating system checked and cleaned regularly by someone qualified to do maintenance.
- Wood-burning stoves should be properly installed. The chimney should be inspected and cleaned by a professional chimney sweep and trash should not be burned in the stove because it could overheat. Gasoline or other flammable liquids should never be used to start wood stove fires.
- Keep portable electric or kerosene heaters out of high-traffic areas. Operate them on the floor at least three feet from upholstered furniture, drapes, bedding and other combustible materials, and turn them off when family members leave the house or go to sleep. Use kerosene heaters only in well-ventilated rooms. Store kerosene outside in a tightly sealed, labeled container.
- Make sure electrical appliances and cords are clean, dry and in good condition.
- Electrical outlets should be grounded. Do not use outlets with several plugs.
- Keep cooking areas free of flammable objects (potholders, towels, etc.).
- Keep storage area above the stove free of flammable/combustible items.
- Wear short or tight sleeves while cooking; do not reach over stove burner.
- Do not leave the stove unattended when cooking, especially when the burner is turned to a high setting.
- Turn pan handles away from burners and the edge of the stove.
- Avoid cooking on high heat with oils and fat.
- Puncture plastic wrap before heating foods in the microwave.
- Never place hot liquids/solids at edge of counter.
- Place layered protection between skin and heating pad.

- Keep electrical appliances away from the bathtub or shower area.
- Never leave patient alone in the shower/tub.
- Set water heater thermostat below 120°F to prevent accidental scalding.
- Store flammable liquids in properly labeled, tightly closed, non-glass containers. Store away from heaters, furnaces, water heaters, ranges and other gas appliances. Make sure the garage is adequately ventilated.

MEDICATION SAFETY

- Do not take medications that are prescribed for someone else.
- Create a complete list of current medications (including prescription and over-the-counter medications, herbal remedies and vitamins), and keep this list with you at all times in the event of emergency situations. Review the list for discrepancies and make changes immediately as they occur. Show the list to your doctor or pharmacist to keep from combining drugs inappropriately.
- Know the name of each of your medicines, why you take it, how to take it, potential side effects and what foods or other things to avoid while taking it.
- Report medication allergies or side effects to your health care provider.
- Take medications exactly as instructed. If the medication looks different than you expected, ask your health care provider or pharmacist about it.
- Drug names can look alike or sound alike. To avoid errors, check with your health care provider if you have questions.
- Do not use alcohol when you are taking medicine.
- Do not stop or change medicines without your doctor's approval, even if you are feeling better. If you miss a dose, do not double the next dose later.
- Use a chart or container system (washed egg carton or med-planner) to help you remember what kind, how much, and when to take medicine.
- Take your medicine with a light on so you can read the label.
- Read medicine labels (including warnings) carefully and keep medicines in their original containers.
- Store medications safely in a cool, dry place according to instructions on the label of the medication.
- Keep medicines away from children and confused adults.
- **Federal disposal guidelines for medications:** Follow any specific disposal instructions on the prescription drug labeling or patient information insert. Do not flush medications down the sink or toilet unless this information specifically instructs you to do so. If your community has a pharmaceutical take-back program, take your unused drugs to them for proper disposal. If no such program is available, remove drugs from their original containers and mark out any identifying information on the original containers. Mix the drugs with an undesirable substance like coffee grounds or kitty litter. Place the mixture in a sealable bag, empty can or other container and place it and the empty, original containers in the trash.

HAZARDOUS ITEMS AND POISONS

- Know how to contact your poison control team.
- Carefully store hazardous items in their original containers.
- Do not mix products that contain chlorine or bleach with other chemicals.
- Purchase insecticides for immediate need only and store excess properly.
- Keep hazardous items, cleaners and chemicals out of reach of children and confused or impaired adults.
- Dispose of hazardous items and poisons only as directed.

MEDICAL EQUIPMENT SAFETY

- Keep manufacturer's instructions with or near specialized medical equipment. Perform routine and preventive maintenance according to the instructions.
- Call Carroll Hospice at **(410) 871-8000** in case of equipment problems or equipment failure.
- Have backup equipment available, if indicated.
- Provide adequate electrical power for medical equipment such as ventilators, oxygen concentrators and other equipment.
- Test equipment alarms periodically to make sure that you can hear them.
- Have equipment batteries checked regularly by a qualified service person.
- Have bedside rails properly installed and use only when necessary. Do not use bed rails as a substitute for a physical protective restraint.
- If bed rails are split, remove or leave the foot-end down so the patient is not trapped between the rails.
- The mattress must fit the bed. Add stuffers in gaps between the rail and mattress or between the head and foot board and mattress to reduce gaps.
- Register with your local utility company if you have electrically powered equipment such as oxygen or ventilator.

OXYGEN SAFETY

- Use oxygen only as directed.
- Oxygen creates a high risk for fire because it causes an acceleration of flame in the presence of flammable substances and open flames.
- **Do not smoke around oxygen.** Post **"No Smoking"** signs inside and outside the home.
- Store oxygen cylinders away from heat and direct sunlight. Do not allow oxygen to freeze or overheat.
- Keep oil/petroleum products (such as Vaseline®, oily lotions, face creams or hair dressings), grease and flammable material away from your oxygen system. Avoid using aerosols (such as room deodorizers) near oxygen.
- Dust the oxygen cylinder with a cotton cloth and avoid draping or covering the system with any material.
- Keep open flames (such as gas stoves and candles) at least 10 feet away from the oxygen source.
- Have electrical equipment properly grounded and avoid operating electrical appliances such as razors and hairdryers while using oxygen. Keep any electrical equipment (including e-cigarettes) that may spark at least 10 feet from the oxygen system.
- Keep at least 6 inches of clearance around an oxygen concentrator at all times. Plug it directly into a wall outlet, and limit the use of extension cords.
- Use 100% cotton bed linens and clothing to prevent static electricity.
- Place oxygen cylinders in appropriate stand to prevent tipping, or secured to the wall or placed on their side on the floor. Store in a well-ventilated area and not under outside porches or decks or in the trunk of a car.
- Have a backup portable oxygen cylinder in case of a power or oxygen concentrator failure.
- Alert property management of oxygen use when living in a multi-dwelling residence.

SECTION VII. Infection Control at Home

Stay clean and use good hygiene to help stop the spread of infection. Items used in health care, such as bandages or gloves, can spread infection and harm the environment. They can harm trash handlers, family members and others who touch them if they are not disposed of properly. Be careful when you handle them.

Some illnesses and treatments (such as chemotherapy, dialysis, AIDS, diabetes and burns) can make people more at risk for infection. Your nurse will tell you how to use protective clothing (such as gowns or gloves) if you need it.

Please tell your doctor or a hospice staff member if you notice any of the following signs and symptoms of infection:

- Pain, tenderness, redness or swelling
- Inflamed skin, rash, sores or ulcers
- Pain when urinating
- Confusion
- Nausea, vomiting or diarrhea
- Fever or chills
- Sore throat or cough
- Increased tiredness or weakness
- Green or yellow pus

WASH YOUR HANDS

Wash your hands frequently and correctly, even if you wear gloves. It is the single most important step in controlling the spread of infection.

Always wash hands before:

- Tending to a sick person
- Treating a cut or wound
- Touching or eating food

Always wash hands after:

- Tending to a sick person
- Treating a cut or wound
- Using the bathroom
- Touching animals or their waste
- Touching soiled linens
- Touching garbage
- Changing diapers
- Coughing, sneezing or blowing your nose

If you have visibly dirty hands, or they are contaminated or soiled in any way, wash them with soap (liquid soap is best) and warm running water. Remove jewelry, apply soap, wet your hands and rub them together for at least 20 seconds. Wash all surfaces, including wrists, palms, back of hands, between fingers and under nails. Rinse off the soap and dry your hands with a clean towel that has not been shared. If one is not available, air-dry your hands. Use a towel to turn off the faucet. If you used paper towels, throw them in the trash. To avoid dry or chapped hands, pat them dry and use lotion after washing.

If you do not have visibly dirty hands, use an alcohol-based hand rub to clean them. Use a rub with 60-90% ethyl or isopropyl alcohol. Open the cap or spout and apply a dime-sized amount (or the amount recommended on the label) in one palm, then rub hands vigorously, covering all surfaces of hands and fingers, until they are dry.

COVER YOUR COUGH

Cover your mouth and nose with a tissue when you cough or sneeze. If you do not have a tissue, cover your mouth with your upper sleeve, not your hands. Throw your used tissue in the trash. You may be asked to wear a mask to protect others.

DISPOSABLE ITEMS AND EQUIPMENT

Some items that are not sharp: *paper cups, tissues, dressings, bandages, plastic equipment, catheters, diapers, Chux, plastic tubing, gloves, etc.*

Store these in a clean, dry area. Throw away used items in waterproof (plastic) bags. Fasten the bags securely and throw them in the trash.

NON-DISPOSABLE ITEMS AND EQUIPMENT

Some items that are not thrown away: *dirty laundry, dishes, thermometers, toilets, walkers, wheelchairs, bath seats, suction machines, oxygen equipment, mattresses, etc.*

Wash dirty laundry separately in hot, soapy water. Handle it as little as possible so you do not spread germs. If the patient has a virus, add a mix of 1 part bleach and 10 parts water to the load.

Clean equipment as soon as you use it. Wash small items (not thermometers) in hot, soapy water, then rinse and dry them with clean towels. Wipe thermometers with alcohol before and after each use. Store them in a clean, dry place. Wipe off equipment with a normal disinfectant or bleach mix. Follow the cleaning instructions that came with the item and ask your nurse or therapist if you have questions.

Pour liquids in the toilet. Clean their containers with hot, soapy water, then rinse them with boiling water and let them dry.

SHARP OBJECTS

Some sharp items: *needles, syringes, lancets, scissors, knives, staples, glass tubes and bottles, IV catheters, razors, etc.*

Put used **sharps** in a clean, hard plastic or metal container with a screw-on or tight lid. Seal it with heavy-duty tape and dispose of it in the trash or according to area regulations. Do not overfill sharps containers or re-cap used needles. **DO NOT use glass** or clear plastic containers. **Never** put sharps in containers that will be recycled or returned to a store.

BODY FLUID SPILLS

Put on gloves and wipe the fluid with paper towels. Use a solution of 1 part bleach and 10 parts water to wipe the area again. Double bag used paper towels and throw them in the trash.

SECTION VIII. Consent Summary

As part of the admission process, we ask for your consent to treat you, release information relative to your care and allow us to collect payments directly from your insurer. **<u>You or your legal representative must sign this consent before we can admit you.</u>**

Consent for Treatment - We require your permission before we can treat you. The treatments that we provide will be prescribed by your doctor and carried out by professional health care staff. Without your consent or the consent of your representative, we cannot treat you.

You may refuse treatment at any time. If you decide to refuse treatment, we will ask you for a written statement releasing us from all responsibility resulting from such action.

Release of Information - Your medical record is strictly confidential and protected by federal law. We may release protected health information as explained in our Notice of Privacy Practices in order to carry out treatment, payment and/or health care operations. Protected health information may be received or released by various means including telephone, mail, fax, etc.

Authorization for Payment - We will directly bill your insurer for the services which we provide to you. You authorize us to collect payments on your behalf.

Advance Directives - You must tell us if you have an advance directive so that we may obtain a copy to allow us to follow your directives. We will provide you care whether or not you have executed an advance directive, but having an advance directive may have an impact on the type of care provided during emergency situations.

CARROLL
HOSPICE

HOSPICE
ADMISSION CONSENT

PATIENT NAME: ____________________

ID#: ____________________ **HOSPICE ELECTION EFFECTIVE DATE:** ____________________

INSTRUCTIONS: This form is used to acknowledge receipt of our orientation booklet and confirm your understanding and agreement with its contents. Your signature below indicates your approval.

PATIENT RIGHTS AND RESPONSIBILITIES I (the patient and/or patient's representative) acknowledge that I have been provided with a written copy of my rights and responsibilities as a patient. A hospice representative has discussed them with me and I understand them. The state home health/hospice hotline number, its purpose and hours of operation have been provided and explained to me. I acknowledge that I have chosen this agency to provide hospice care. No employee of this agency has solicited or coerced my decision in selecting a hospice agency.

CONSENT FOR TREATMENT I consent to have Carroll Hospice provide any and all examinations and treatments as prescribed by his/her physician. Such treatments will be rendered according to hospice policies and procedures. I understand the following hospice care and services may be provided to them during the course of illness: physician, nursing, social work, therapy services, counseling services (spiritual, dietary and bereavement), hospice aide/homemaker, volunteers, durable medical equipment, pharmaceuticals, medical supplies, respite care, short term inpatient care and continuous care. I consent to follow the Carroll Hospice policies and procedures relating to hospice care, which have been reviewed with me and which include provisions for termination of services at my request, the physician's request and/or Carroll Hospice's request.

AUTHORIZATION FOR RELEASE OF INFORMATION AND PAYMENT I acknowledge receipt of the **Notice of Privacy Practices** and was given an opportunity to ask questions and voice concerns. I understand that the agency may use or disclose protected health information about me to carry out treatment, payment or health care operations. I consent to the release of Carroll Hospice records to representatives of Medicare/Medicaid, Medicare Intermediary and/or private insurance companies for use in obtaining payment via my hospice benefits. Such records will also be available to all Health and Social Service agencies rendering medical or social services to me, including, but not limited to, medical review committees, accreditation boards or in response to legal process.

ASSIGNMENT OF BENEFITS I certify that the information given in applying for payment under Title XVIII of the Social Security Act or other insurance, is correct. Payment of authorized hospice benefits is to be made directly to Carroll Hospice on my behalf.

AUTHORIZATION FOR PAYMENT/ELECTION OF HOSPICE CARE I certify that the information given by me in applying for payment under Title XVIII of the Social Security Act is correct. I authorize release of all records required to act on this request. I request that payment of authorized benefits from Medicare, Medicaid or other responsible payor be made in my behalf to Carroll Hospice. I understand that I am responsible for all amounts not paid by my insurance. If I am a Private Pay patient, I agree to pay for all services rendered by the hospice. I hereby elect to participate in hospice care under the following checked program:

☐ **Medicare Hospice Benefit** ☐ **Commercial Insurance Hospice Benefit** ☐ **Private Pay**

If I have Medicare Part A benefits, I understand that Medicare payments will be accepted as payment in full and I have no financial liability, unless I have been notified in writing that service(s) will not be covered by Medicare and wish to receive the care or service. If I have other insurance, I may be responsible for the co-payment and any charges that my insurance will not cover.

Medicare, Medicaid, or Insurance will cover ________ % and my responsibility is ________ %

I will be responsible for $ ____________________ My insurance company will be responsible for: ____________________

SPECIAL SERVICES I understand that, if I need hospitalization or special services not provided by the agency, I or my legal representative must make arrangements for these services. The agency shall in no way be responsible for failure to provide the same and is hereby released from any liability arising from the fact that I am not provided with such additional care.

ADVANCE DIRECTIVES I understand that the Federal Patient Self-Determination Act of 1990 requires that I be made aware of my right to make health care decisions for myself. I understand that I may express my wishes in a document called an Advance Directive so that my wishes may be known when I am unable to speak for myself.

1. **I have made Health Care Instructions** ☐ **No** ☐ **Yes** 2. **I have appointed a Health Care Agent** ☐ **No** ☐ **Yes**
   (If yes, write the name and phone number of your Health Care Agent.) ____________________
3. **Further Directive if diagnosed with an irreversible disease:**
   I have been informed that I have an irreversible disease ☐ **No** ☐ **Yes**
   I wish to receive **resuscitative measures:** ☐ **No** ☐ **Yes**
   I wish to receive **artificial hydration and nutrition:** ☐ **No** ☐ **Yes**
4. **I have completed a MOLST (Medical Orders for Life Sustaining Treatment)** ☐ **No** ☐ **Yes**
   I want to complete/change a MOLST ☐ **No** ☐ **Yes**

PRIMARY CAREGIVER CONSENT I, ____________________, agree to accept the role of primary care person for the above named patient who is my ____________________. I have a commitment to have him/her remain at home during this terminal illness, but to provide care and comfort of a physical, emotional, spiritual and practical nature. I understand my obligations as primary care person are as follows: ☑ I will be responsible for caring for him/her at home.

☑ I will be responsible for arranging for his/her care should I become unable to provide such care myself.

I understand the obligations of Carroll Hospice as follows: ☑ The hospice team will instruct me on necessary care techniques and assist me in providing care. ☑ The hospice team will provide emotional and spiritual support to me during this illness and through the bereavement period of 13 months. It is the policy of Carroll Hospice that all patients living alone at the time of admission will formulate a plan of care for when they are no longer independent. I agree to plan with the hospice social worker for my care when I am no longer independent.

Patient Signature	Date	Responsible Person or Legal Guardian Signature
Agency Representative Signature	Date	Printed Name and Relationship of Person Above

☐ *Patient unable to sign due to:* ____________________

Form #105-Carroll, Rev. 2/16

CARROLL
HOSPICE

MEDICARE SECONDARY PAYER WORKSHEET

PATIENT NAME: ______________________ **PATIENT ID:** ____________

KEY: *WC = Workers Compensation* **BL** *= Black Lung* **GHP** *= Group Health Plan* **ESRD** *= End Stage Renal disease* **DVA** *= Dept of Veterans Affairs*

PART I: Was illness/injury due to a **Work Related Accident/Condition** and covered by WC plan, DVA or the Federal BL Pgm.?

☐ **NO: Continue to Part II**

☐ **YES:** Name & Address of: ☐ **WC** ☐ **DVA** ☐ **BL** Pgm. *(check all that apply)*

____

______________ Policy or ID #: ______________

PRIMARY PAYER FOR CLAIMS RELATED TO:
☐ ***DVA- Dept of Veterans Affairs** (Go to Part III)*
☐ ***WC- Workers' Comp.***
☐ ***BL- Black Lung***

PART II: Was illness/injury due to a **Non-Work Related Accident/Condition?**

☐ **NO: Continue to Part III**

☐ **YES:** What type of accident caused the injury? ☐ **Automobile** ☐ **Non-Automobile**

Accident Location: ☐ Home ☐ Business ☐ Other: ____________ **Date of Accident/Injury:** ________

Describe Accident/Injury: ______________________

☐ **Automobile?** Name, Address & Phone # of Insurer: ______________________

Insurance claim number: ______________________

YES: STOP ***AUTO INSURER IS PRIMARY PAYER FOR ACCIDENT RELATED CLAIMS*** *(Go to Part III)*

☐ **Non-Automobile?** Was another party responsible for this accident?

Name, Address & Phone # of any liability insurer: ______________________

Insurance Claim Number: ______________________

STOP ***ANOTHER PARTY IS PRIMARY PAYER FOR ACCIDENT RELATED CLAIMS*** *(Go to Part III)*

PART III: Is Patient **Entitled to Medicare Based on Age** (age 65 or over)? (If Yes, answer questions 1 - 3)

☐ **NO:** *(Under age 65)* **Continue to Part IV**

☐ **YES:**

1. Is the patient ☐ ***employed*** ☐ ***retired*** and covered by GHP or HMO? ☐ Yes ☐ No
(retirement date: ____________) ☐ No *Never worked*

or 2. Is the patient covered under spouse's GHP or HMO? ☐ Yes ☐ No

or 3. Has the patient chosen an HMO to manage their medicare benefits? ☐ Yes ☐ No

and **Does GHP employ 20 or more?** ☐ Yes ☐ No

If questions 1-3 are NO then ***MEDICARE IS THE PRIMARY PAYER*** STOP *unless part I or II was answered YES*

STOP ***GHP/HMO IS THE PRIMARY PAYER*** (Go to Part VI) **Complete GHP/HMO Information** (Part VI)

PART IV: Patient is a **DISABLED Medicare Beneficiary Under Age 65.**

and 1. Is the patient covered by GHP or HMO? ☐ No ☐ Yes **(GHP employs 100 or more ☐ Y ☐ N)**

or 2. Is the patient covered under spouse's GHP or HMO? ☐ No ☐ Yes **(GHP employs 100 or more ☐ Y ☐ N)**

☐ **NO:** STOP ***MEDICARE IS THE PRIMARY PAYER*** - *(Questions 1 & 2 are* ***NO****)* *(unless part I or II was answered* ***YES****)*

☐ **YES:** **Continue to Part V** (and complete Part VI) **Complete GHP/HMO Information** (Part VI)

PART V: Is Patient entitled to Medicare based on **End Stage Renal Disease (ESRD)?** (Primary Payer Determination)

☐ **NO:** STOP ***MEDICARE IS THE PRIMARY PAYER***

☐ **YES:**

1. Is the patient within the **30 month coordination period**? *(i.e., 30 mo. from initiation of dialysis?)* ☐ Yes ☐ No
2. Was the patient's initial entitlement to Medicare based on ESRD? ☐ Yes ☐ No
3. Does the working aged or disability MSP provision apply? (i.e., is the GHP primary based on age or disability entitlement?) ☐ Yes ☐ No

If questions 1-3 are NO then MEDICARE IS THE PRIMARY PAYER STOP

STOP ***GHP/HMO IS THE PRIMARY PAYER DURING THE 30 MO. COORDINATION PERIOD.*** *(1 & 2 or 1 & 3 is YES)*

Complete GHP/HMO Information (Part VI)

PART VI. GHP/HMO INFORMATION

Name/Phone # of Employer *(if appl.)*: ______________________

Name & Address of GHP/HMO: ______________________

Patient's ID number: ______________________

Policy Holder/Relation to patient: ______________________

SIGNATURE/TITLE: ______________________ **DATE:** ____________

FORM # 111, Rev. 2/05

CARROLL HOSPICE

HOSPICE ADMISSION CONSENT

PATIENT NAME: ______________________________

ID#: ____________________ **HOSPICE ELECTION EFFECTIVE DATE:** ____________________

INSTRUCTIONS: This form is used to acknowledge receipt of our orientation booklet and confirm your understanding and agreement with its contents. Your signature below indicates your approval.

PATIENT RIGHTS AND RESPONSIBILITIES I (the patient and/or patient's representative) acknowledge that I have been provided with a written copy of my rights and responsibilities as a patient. A hospice representative has discussed them with me and I understand them. The state home health/hospice hotline number, its purpose and hours of operation have been provided and explained to me. I acknowledge that I have chosen this agency to provide hospice care. No employee of this agency has solicited or coerced my decision in selecting a hospice agency.

CONSENT FOR TREATMENT I consent to have Carroll Hospice provide any and all examinations and treatments as prescribed by his/her physician. Such treatments will be rendered according to hospice policies and procedures. I understand the following hospice care and services may be provided to them during the course of illness: physician, nursing, social work, therapy services, counseling services (spiritual, dietary and bereavement), hospice aide/homemaker, volunteers, durable medical equipment, pharmaceuticals, medical supplies, respite care, short term inpatient care and continuous care. I consent to follow the Carroll Hospice policies and procedures relating to hospice care, which have been reviewed with me and which include provisions for termination of services at my request, the physician's request and/or Carroll Hospice's request.

AUTHORIZATION FOR RELEASE OF INFORMATION AND PAYMENT I acknowledge receipt of the **Notice of Privacy Practices** and was given an opportunity to ask questions and voice concerns. I understand that the agency may use or disclose protected health information about me to carry out treatment, payment or health care operations. I consent to the release of Carroll Hospice records to representatives of Medicare/Medicaid, Medicare Intermediary and/or private insurance companies for use in obtaining payment via my hospice benefits. Such records will also be available to all Health and Social Service agencies rendering medical or social services to me, including, but not limited to, medical review committees, accreditation boards or in response to legal process.

ASSIGNMENT OF BENEFITS I certify that the information given in applying for payment under Title XVIII of the Social Security Act or other insurance, is correct. Payment of authorized hospice benefits is to be made directly to Carroll Hospice on my behalf.

AUTHORIZATION FOR PAYMENT/ELECTION OF HOSPICE CARE I certify that the information given by me in applying for payment under Title XVIII of the Social Security Act is correct. I authorize release of all records required to act on this request. I request that payment of authorized benefits from Medicare, Medicaid or other responsible payor be made in my behalf to Carroll Hospice. I understand that I am responsible for all amounts not paid by my insurance. If I am a Private Pay patient, I agree to pay for all services rendered by the hospice. I hereby elect to participate in hospice care under the following checked program:

☐ **Medicare Hospice Benefit** ☐ **Commercial Insurance Hospice Benefit** ☐ **Private Pay**

If I have Medicare Part A benefits, I understand that Medicare payments will be accepted as payment in full and I have no financial liability, unless I have been notified in writing that service(s) will not be covered by Medicare and wish to receive the care or service. If I have other insurance, I may be responsible for the co-payment and any charges that my insurance will not cover.

Medicare, Medicaid, or Insurance will cover ________% and my responsibility is ________%

I will be responsible for $ ____________________ My insurance company will be responsible for: ____________________

SPECIAL SERVICES I understand that, if I need hospitalization or special services not provided by the agency, I or my legal representative must make arrangements for these services. The agency shall in no way be responsible for failure to provide the same and is hereby released from any liability arising from the fact that I am not provided with such additional care.

ADVANCE DIRECTIVES I understand that the Federal Patient Self-Determination Act of 1990 requires that I be made aware of my right to make health care decisions for myself. I understand that I may express my wishes in a document called an Advance Directive so that my wishes may be known when I am unable to speak for myself.

1. **I have made Health Care Instructions** ☐ No ☐ Yes 2. **I have appointed a Health Care Agent** ☐ No ☐ Yes
(If yes, write the name and phone number of your Health Care Agent.) ______________________________

3. **Further Directive if diagnosed with an irreversible disease:**
   - I have been informed that I have an irreversible disease ☐ **No** ☐ **Yes**
   - I wish to receive **resuscitative measures:** ☐ **No** ☐ **Yes**
   - I wish to receive **artificial hydration and nutrition:** ☐ **No** ☐ **Yes**
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______________________________ Patient Signature ____________ Date ______________________________ Responsible Person or Legal Guardian Signature

______________________________ Agency Representative Signature ____________ Date ______________________________ Printed Name and Relationship of Person Above

Patient Copy

☐ *Patient unable to sign due to:* ______________________________

Form #105-Carroll, Rev. 2/16

Notes

CARROLL HOSPICE

CONSENT FOR ELECTION OF MEDICARE HOSPICE BENEFIT

PATIENT NAME: ______________________________ **ID#:** ____________________ **DATE:** ______________

INFORMED CONSENT

I ACKNOWLEDGE/UNDERSTAND THE FOLLOWING:

I understand the nature of the hospice care available through the Medicare Hospice Benefit and am aware that all treatment will focus on comfort (palliative) rather than cure (curative) or life prolonging. Treatment will be for management of symptoms and to provide comfort for my terminal illness. The focus of my care will be to maintain me in my home rather than in a hospital.

I understand that I or my representative have the right to choose my attending physician. My attending physician is ______________________________. NPI #: ______________________.

I understand that I and/or my caregiver will participate in developing the plan of care along with the hospice team composed of a physician, nurse, medical social worker, spiritual counselor, volunteer and other disciplines that may be necessary.

I waive the right to all other benefits under the Medicare Program for care related to my terminal diagnosis while I am receiving hospice benefits. Only Carroll Hospice will be able to receive Medicare payment for care of services provided to me for my terminal illness or any other condition related to my terminal illness.

Medicare will make payment for unlimited hospice days; however, the days are broken into three benefit periods to be used in this order. These periods are as follows:

First Benefit Period	- 90 days
Second Benefit Period	- 90 days
Subsequent 60 day Period	- Unlimited as long as beneficiary meets requirement for benefit.

Prior to the beginning of each benefit period, my medical condition will be evaluated for continued hospice appropriateness by my physician and the hospice team.

I understand that I can use standard Medicare in the usual manner to pay the bill for:

1. My doctor, if not an employee of this hospice.
2. Treatment of a condition unrelated to my terminal illness. (See above.)

I understand that I can revoke this benefit at any time and resume regular Medicare coverage. I know I will lose any hospice days remaining in the benefit period in which I revoke.

I understand that I may transfer my hospice care to another Hospice Program once during each election period.

I acknowledge that the Attending Physician identified above is my choice: ____________ (initials)

ACKNOWLEDGING/UNDERSTANDING THE ABOVE, I AUTHORIZE MEDICARE HOSPICE BENEFIT COVERAGE TO BEGIN ON: ______________________________.
Month/Day/Year

______________________________ ______________
Beneficiary or Representative Signature — Date

____
Relationship of Legal Representative to Beneficiary

______________________________ ______________
Hospice Representative Signature — Date

CARROLL
HOSPICE

CONSENT FOR ELECTION OF MEDICARE HOSPICE BENEFIT

PATIENT NAME: ______________________________ **ID#:** ____________________ **DATE:** ______________

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ACKNOWLEDGING/UNDERSTANDING THE ABOVE, I AUTHORIZE MEDICARE HOSPICE BENEFIT COVERAGE TO BEGIN ON: ________________________________.
Month/Day/Year

____ ______________________
Beneficiary or Representative Signature Date

____
Relationship of Legal Representative to Beneficiary

____ ______________________
Hospice Representative Signature Date

Form 105-E, Rev. 2/16

CARROLL
HOSPICE

HOME VISIT SCHEDULE

MONTH: ____________________

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
☐	☐	☐	☐	☐	☐	☐
☐	☐	☐	☐	☐	☐	☐
☐	☐	☐	☐	☐	☐	☐
☐	☐	☐	☐	☐	☐	☐
☐	☐	☐	☐	☐	☐	☐
☐	☐	☐	☐	☐	☐	☐

For any questions or concerns, please contact your Clinical Manager at (410) 871-8000

Form #182-SHC, Rev. 8/00

CARROLL HOSPICE

(410) 871-8000

Your Hospice Team Staff Names

Nurse Case Manager: ______________________

Social Worker: ______________________

Hospice Aide: ______________________

Hospice Medical Director: ______________________

Therapist: ______________________

Spiritual Counselor: ______________________

Volunteer(s): ______________________

Attending Physician: ______________________

Your Hospice Medicare and Contracted Per Diem Services

for Approved Medications, Equipment and Hospitalization are:

HME (Oxygen) ______________________

Hospital ______________________

Pharmacy ______________________

Funeral Home ______________________

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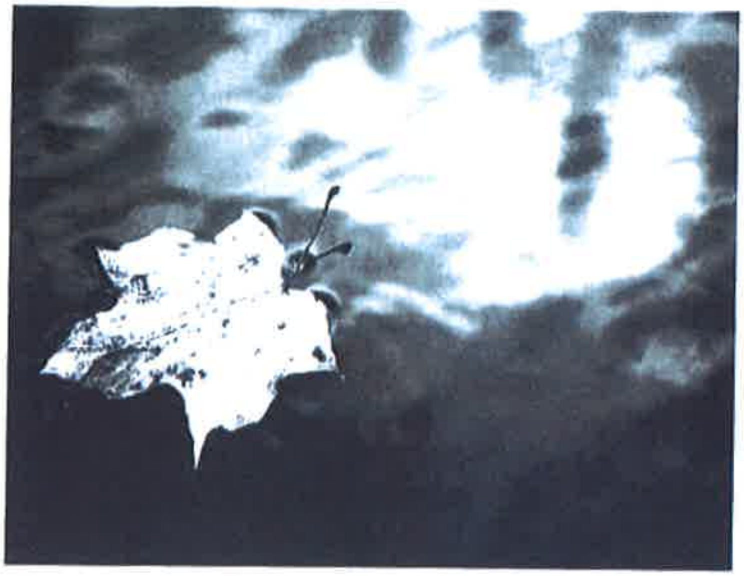
When the Time Comes Booklet



When the Time Comes

A CAREGIVER'S GUIDE

CARROLL
HOSPICE

May the longtime sun shine upon you,
All love surround you,
And the pure light within you
Guide you on your way.

Introduction

Dying is a natural part of life, but many people do not have experience caring for someone during the dying process and find themselves navigating through new and unfamiliar territory. It is not uncommon to experience a wide range of emotions and a sense of uncertainty. At times you may feel that you are on a roller coaster, not knowing what to expect next. This booklet is designed to help you feel more confident in knowing what to expect and what you can do to care for someone in the final weeks and hours of life.

Family members, friends, and caregivers can play an important role in providing comfort and support to someone entering this final phase of life. Sometimes it is not so much what you say or do, but just being present with another, that can provide a sense of reassurance and comfort.

Each person's dying experience is unique, and no one can fully predict what it will be like or when it will occur. However, we hope the information contained in this booklet will provide some landmarks to help guide the way. Please contact hospice at any time for further information and support. It is our goal to respect the dignity of each person by providing quality comfort care.

Table of Contents

End-of-Life Developmental Milestones and Tasks

Source: Dr. Ira Byock

Dr. Ira Byock is a leader and educator in promoting quality care at the end of life. Below is a framework he developed that outlines some of the issues many people may be contemplating as they approach death. His findings are included here as part of a holistic understanding of the dying process. Although the journey toward death may not be easy, it can often be a time of new insights, personal growth, and inner healing.

- Sense of completion with worldly affairs
- Sense of completion in relationships with community
- Sense of meaning about one's individual life
- Experiencing love of self
- Experiencing love of others
- Sense of completion in relationships with family and friends
- Acceptance of the finality of life – of one's existence as an individual
- Sense of a new self (personhood) beyond personal loss
- Sense of meaning about life in general
- Surrendering to the transcendent, to the unknown – "letting go"

Withdrawal

It is common for people to begin to withdraw from friends, family, and the world around them as a normal part of the dying process. This process may begin as early as weeks before the death. The dying person may stay in bed all day and spend more time asleep than awake. With the withdrawal comes less of a need to communicate with others; touch and silence take on more meaning. People at this point may seem unresponsive and difficult to arouse or may appear to be in a coma-like state. This detaching from surroundings and relationships may be preparation for release and letting go.

What you can do:

- Plan activities and visits for times of day when the person seems most alert.
- Because hearing remains intact to the end, speak to the person in your normal tone of voice.
- Identify yourself by name when you speak. Tell the person what you are going to do before you do it. For example: "Bob, this is Karen. I'm going to clean your mouth now."
- Remember not to say anything in front of the person that you wouldn't say if he or she were awake.

Changes in Appetite

Near the end of life, it is natural for a person to no longer be interested in food or to be unable to eat or drink. Often nothing tastes good, and cravings come and go. This is often one of the hardest concepts for caregivers to accept because food is the way we nourish the body and share family time together.

As the body naturally begins to slow down, it is no longer able to digest and assimilate food in the same way. Weight loss is expected and does not mean that the person is hungry or being "starved" by the absence of food.

What you can do:

- Let the person be the guide; he or she will let you know if food or fluids are needed or wanted.
- Liquids are preferred to solids. Some people find thickened liquids easier to swallow. Small chips of ice or frozen juice may be refreshing in the mouth. If the person is able to swallow, fluids may be given in small amounts by syringe (without a needle) or dropper (ask the hospice nurse for guidance).
- There may be times when the taste or smell of familiar foods in small amounts is comforting.
- People who can't speak will sometimes cough, bite the spoon, clamp their teeth closed, turn their heads, or spit food out to let you know they don't want to eat.
- Respect the person's wishes by trying not to force food or drink. Often a person near death may appear thirsty but won't be able to drink water. Frequent mouth care may provide comfort; use swabs to keep the mouth and lips moist.

Changes in Elimination

Incontinence is the loss of control of the bladder and bowels that can sometimes occur as the muscles in the lower body begin to relax. As people decline, the urine output usually diminishes, and the color is usually darker than normal. It may also be cloudy or have a strong odor. This is the normal response to the decreased fluid intake as well as decreased circulation through the kidneys.

Unfortunately, incontinence can be a source of shame and embarrassment for many people. Keeping the person clean, dry, and comfortable, as well as preserving dignity, is the overall goal.

What you can do:

- Adult disposable briefs and underpads on the bed may solve the problem. The nurse or home health aide can show you how to change these for someone in bed.
- In some situations it may be appropriate for the nurse to suggest placing a catheter (a tube) into the bladder to keep the person's skin from being constantly wet. There may be a few seconds of discomfort as the catheter is inserted, but then there is generally no awareness of it at all.
- The nurse may suggest that certain lotions or creams be applied to the skin periodically.
- To help maintain dignity, provide privacy when changing pads or providing personal care. Check the person frequently to ensure that he or she is kept dry and comfortable.

Changes in Breathing

Breathing patterns often begin to change for those nearing the end of life. Breathing may slow down, or there may be rapid, shallow breaths followed by periods of no breathing. These periods can last 5 to 30 seconds, or even up to a full minute. This kind of breathing is not uncomfortable for the person but is a response to the body's weakening condition. Your hospice nurse, along with your physician, will assess and determine if oxygen would be a comfort measure at this time.

Sometimes when individuals are so weak that they can't swallow, saliva gathers in the back of the throat and makes a "rattling" sound. Suctioning usually only increases the secretions and causes discomfort. This sound may be distressing to hear, but it does not indicate that the person is suffering.

What you can do:

- Gently turning the person on his or her side may assist gravity to drain the secretions. Raising the head of the bed may also help.
- Your nurse may educate you about prescribed medications that will dry excess secretions.
- At this point the person is usually breathing with his or her mouth open. This will make the mouth very dry, so frequent mouth care is important.
- If breathing seems labored, your doctor may prescribe morphine or a similar medication to ease the breathing and provide comfort.

Changes in Body Temperature

FEVER

As the body becomes weaker, so does the temperature control mechanism in the brain. This can cause the person to have a fever or cause the body to become cool. Sometimes a person may become sweaty and clammy with or without a fever.

What you can do:

- If a fever develops, let your hospice nurse know. Often placing a cool wash cloth on the forehead and removing blankets may be all that is needed. However, your hospice nurse may suggest an over-the-counter pain reliever (such as acetaminophen) if the fever is high. As the fever lowers, the person may perspire, requiring a change of gown, pajamas, and sheets to provide more comfort.
- Consider using a fan or opening a window.
- If the person throws the covers off, it is important to remember that he or she may be warm even when you feel cool.

COOLNESS

As your loved one becomes weaker, his or her circulation decreases. You may notice that extremities feel cool to the touch and skin color may change. The hands and feet may become purplish, and the knees, ankles, and elbows may look blotchy. The person may appear pale and have a bluish cast around the lips and under the fingernails. This state doesn't cause any discomfort for the person and is a natural part of the dying process.

What you can do:

- Use a warm blanket, but not an electric blanket.
- Continue to gently reposition the person, or provide gentle massage.

Confusion and Disorientation

At times, people nearing the end of their life may have confusion about the time, their surroundings, and the identity of those around them. They may report seeing people or things that are not visible to others, and they may engage in conversation with others who are not visibly present or who have already died.

People near the end of life will sometimes talk about travel, as though they are planning a journey. They may say things such as: "I want to go home," "I want to get my keys," "I need to find my suitcase," or "Where is the train/bus?" This type of conversation is referred to as symbolic language, and may be one of the ways people let us know that they are preparing for death or are trying to tell us goodbye.

When these symptoms are present, we may wonder if the person is taking too much medicine or not enough. Most often, these symptoms are a normal part of the dying process. The hospice nurse will assess the prescribed medication at each visit and determine along with the physician if it is the correct medicine at the correct dosage.

What you can do:

- Report these symptoms to the hospice nurse or other hospice team members; they will assess and provide information on ways you can provide care and support at this time.
- If appropriate, gently try to reorient the person. Remind them of who you are and what you are going to be doing, and point out familiar landmarks in their surroundings.
- Provide reassurance by reminding them of your presence and support, and that you will take care of them and keep them safe.
- Sometimes limiting visitors can decrease the level of confusion or disorientation.

- Allow and acknowledge whatever experience the person may be having, without trying to contradict or argue it away. This experience is real to them, even though it may not seem real to you.
- Listen carefully; there may be meaningful messages being shared in symbolic language.
- You may want to keep a journal to record some of the meaningful things that are shared. This may be a source of inspiration and comfort to share with other family members.

"You don't have to do or say anything to make things better. Just be there as fully as you can."

— Sogyal Rinpoche

Restlessness and Agitation

At times, the person you are caring for may appear restless or unable to be still, and may pick at bed clothes or perform repetitive movements. This is not uncommon and may be due to a variety of physical or emotional reasons.

Restlessness may be caused in part by a slowing down of circulation, causing less oxygen to flow to the brain. Sometimes restlessness or agitation can be a symptom of physical discomfort or pain. Emotional or spiritual concerns, such as an unresolved issue or unfinished task, can be worrisome and also cause feelings of uneasiness or restlessness.

What you can do:

- Let the hospice nurse know if the person is agitated or restless. The nurse will assess for any underlying pain or discomfort.
- Continue with the medication regimen prescribed by the doctor.
- Utilize the hospice social worker and/or chaplain to address underlying concerns and provide emotional or spiritual support.
- Provide a reassuring presence by speaking slowly, calmly, and in a soothing way.
- If appropriate, help the person resolve issues and complete tasks. Sometimes offering to take over a task or suggesting it be delegated to another trusted person can provide relief.
- Try reading something inspirational or playing soft music.
- Holding hands or a light touch may be reassuring.

- Use bed rails or have someone sit with the person to keep him or her safe.
- Consider use of a baby monitor while out of the room.
- Restraints may cause further agitation and are not encouraged.
- It may be useful to limit visitors at this time and to minimize outside distractions (loud noises, radio or TV, ringing phones).
- Some people find comfort in sharing memories about special occasions or holidays, family experiences, or the memory of a favorite place.

"Among the best things we can give each other are good memories."

— Henry Nouwen

Surge of Energy

Dying loved ones may exhibit sudden unexplained surges of energy, which are usually short-lived. They may become unexpectedly alert and clear, ask to eat when they haven't had food for days, or they may want to get up to visit when they haven't been out of bed for weeks. This doesn't always happen in such dramatic ways but can be more subtle, such as being awake more when they have been sleeping most of the time. It is easy to see how this could be misunderstood and can give false hope that the individuals are getting better. It may be that they are marshalling all their physical strength for their last full-body experience in this life.

What you can do:

- Enjoy this time for what it is.
- Use the time to reminisce and say goodbye.
- Be together holding hands.

> *"The things that matter most in our lives are not fantastic or grand. They are the moments when we touch one another, when we are there in the most attentive or caring way."*
>
> *— Jack Kornfield*

Saying Goodbye

Many people have questions about saying goodbye and wonder whether it is appropriate to do so. Some are concerned that it will hasten death or communicate something unintended. Others may want to say goodbye but may not know what to say. In addition, some families have questions about whether they should give permission to let go.

When and how to say goodbye is a personal decision, and there is no right or wrong way to do it. Some families have difficulty starting the conversation but find that once begun, it can be a gift. This time with your loved one is precious.

What you can do:

- Take this opportunity while the person is alert to say or do what you need to.
- Listen to the wisdom of your heart, and follow its guidance.
- Some families begin these conversations with:
    - *"What I love most about you..."*
    - *"What I will always remember..."*
    - *"What I will miss most about you..."*
    - *"What I learned from you..."*
    - *"What I will cherish..."*
- Some people may choose this time to say, "I am sorry," share forgiveness, or let go of past conflicts.
- Some people may choose this time to share expressions of gratitude.
- It may be helpful to lie in bed with your loved one and hold them, or take their hand and say everything you need to say.
- Tears are a normal and natural part of saying goodbye, and could be a healthy expression of your love.

Review of Possible Signs and Symptoms of Approaching Death

Because each person's dying process is unique to him or her, the outline below is only a general guide. People may exhibit some or all of these signs and symptoms at varying times.

ONE TO THREE MONTHS

- Withdrawal from people and activities
- Communicating less
- Eating and drinking less
- Sleeping more

ONE TO TWO WEEKS

- Disorientation and confusion
- Use of symbolic language ("I want to go home")
- Talking to others not present in the room
- Physical changes:
  - – Increase or decrease in pulse
  - – Decrease in blood pressure
  - – Changes in skin color
  - – Irregularities in breathing
  - – Changes in body temperature, hot/cold
  - – Not eating, taking little or no fluids

DAYS TO HOURS

- Sleeping most of the time
- Surge of energy
- Restlessness
- Difficulty swallowing
- Further discoloration of skin
- Ongoing changes in breathing (long pauses between breaths)
- Rattling breath sounds
- Weak pulse
- Further decrease in blood pressure
- Decreased urine output or no urine
- Eyelids no longer able to close completely

MINUTES

- Shallow breaths with longer pauses
- Mouth open
- Unresponsive

"In this life we cannot do great things. We can only do small things with great love."

— Mother Teresa

Moment of Death

It is important to discuss with family members, caregivers, and friends what to do if they are present at the time of death. No one can accurately predict when death may occur. Some people die when others are present. Some take their last breaths when they are alone.

When the person has died, there will be no breathing or heartbeat. There will be no response to your voice or touch. The eyes may be partly open, and the pupils will be unresponsive. The jaw will relax, and the mouth will open. Sometimes there will be loss of bowel and bladder control.

No matter how well prepared you are, death can still feel like a shock. At the time of death, nothing needs to be done immediately other than calling hospice. There is no need to call 911 or notify the police. You may want to call a trusted friend or a family member to be with you at this time.

What you can do:

- Please contact hospice. A nurse will visit. Please note that other team members may provide assistance as needed.
- When a nurse or other team members visit, some of the things they may do are:
    - Confirm the death
    - Remove any tubes that are present
    - Offer to bathe and prepare the body
    - Dispose of medications
    - Call the funeral home, if you wish
    - Provide support
    - Notify the physician and your hospice team, and arrange for medical equipment to be removed

- People honor the passing of their loved ones in a variety of ways. Some choose to have the funeral home come right away, while other families may choose to wait for a period of time before calling.
- Some of the ways in which you can honor your loved one are: bathing and dressing the body in special clothes, telling stories, lighting a candle, sharing a ritual from his or her spiritual tradition, placing flowers in the room, or playing special music.
- Let the funeral home staff know when you are ready for them to arrive. When they do come, you can decide whether you want to be present when they remove the body or wait in another part of the house. The funeral home will let you know about making arrangements for services.

"Our life is a faint tracing on the surface of mystery."

—Annie Dillard

Care for the Caregiver

Caring for someone who is in the final weeks and days of life can be physically and emotionally demanding. It may feel overwhelming at times and leave you weary in body, mind, and spirit. In addition, some caregivers are often juggling other responsibilities such as work, household duties, caring for other family members, or addressing their own health concerns. Trying to balance another's care with your own needs for rest and nourishment is challenging, but important for your own wellbeing.

What you can do:

- Take a deep breath several times a day. Deep breathing brings more oxygen to every cell and can refresh both body and mind.
- Go outside for a few minutes; smell and feel the fresh air. Take a walk or sit in your garden.
- If you have an exercise routine, try to adhere to it, as this can help decrease stress and boost energy.
- Lie down for 20 minutes or sit in a recliner with your feet up.
- Drink plenty of liquids, especially water.
- Follow a well-balanced diet, eating at regular intervals. Your health and nutrition are just as important as that of the person for which you are caring.
- Determine if calls or visits are helpful or would cause more stress. Limit these as a way of honoring your own needs and private time.
- Ask for help. Often family and friends want to help but do not know how. Keep a list of tasks to be done, such as shopping, going to the post office, walking the dog, or going to the pharmacy.
- Utilize a hospice volunteer visitor for respite or for help with errands.
- Share your concerns or feelings with a trusted friend, your spiritual counselor, or someone from your hospice team.

What to Expect at the End of Life Rack Card

Carroll
Hospice

What to Expect at the End of Life

As body systems slow down and function less effectively, you may notice some changes in your loved one. Some or all of the following may occur:

- Increased sleeping/more difficult or unable to awaken
- Increased restlessness, including pulling at clothes and shaky hands
- Confusion or hallucinations, such as talking with people not in room
- Changes in skin color: skin becomes pale/waxy or has a blue tinge, especially on legs and arms
- Decreased or no fluid and food intake
- Breathing changes, including shortness of breath, increased breathing rate, noisy snoring breaths, periods of shallow breaths or periods of no breaths for several seconds
- Fever
- Increased pain
- Decrease in urine output decreases or inability to hold urine or bowels

Although these symptoms are a normal part of the dying process, they may cause you concern. Please make your nurse aware of these changes at her visit or call the hospice office at **410-871-8000** to talk with a nurse between visits.

What to Do When Death Occurs

1. Call Carroll Hospice at 410-871-8000.
2. Call any family members who may want to be with patient before funeral home arrives at the home.
3. A nurse will make a visit to the home and nurse will contact the funeral home for you.

Medications that May be Used in Hospice

- Ativan/Lorazepam — to control restlessness
- Morphine/Roxanol — to control pain
- Atropine — to dry secretions
- Scopolamine — to dry secretions

Falls Prevention Brochure

Falls can be caused by numerous factors, including:

- Safety hazards in the environment
- Poor balance
- Weakness
- Illness
- Fragility of health
- Changes in blood pressure
- Medications

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WE HONOR VETERANS

CHAP

6/16

Falls Prevention for *patients* and Families

CARROLL HOSPICE

Why is fall prevention important?

A fall can result in a wide range of injuries that can affect a patient's comfort and quality of life. Your hospice team is dedicated to improving the quality of life for our patients by providing palliative care, pain and symptom management, and support to patients and their families. A patient's fall risk is evaluated periodically throughout his or her care, and the hospice team will make recommendations designed to reduce the risk of falls.

fall facts

Falls are the leading cause of both fatal and non-fatal injuries.

More than one-third of adults ages 65 and older fall each year in the United States.

Fall Prevention Tips

Environmental:

- Remove obstacles (clutter, throw rugs and cords) and rearrange furniture for clear pathways
- Remove objects from all stairways
- Provide adequate lighting throughout the home, including nightlights
- Add handrails or grab bars in bathrooms and hallways
- Place nonslip mats in the bathtub
- Place frequently used items in easy-to-reach cabinets/areas
- Keep emergency numbers in a visible place
- Keep phone within reach

Medical:

- Notify your nurse of any medication changes
- Notify your nurse of any changes in symptoms
- Discuss with your nurse the possible side effects of medications

Physical:

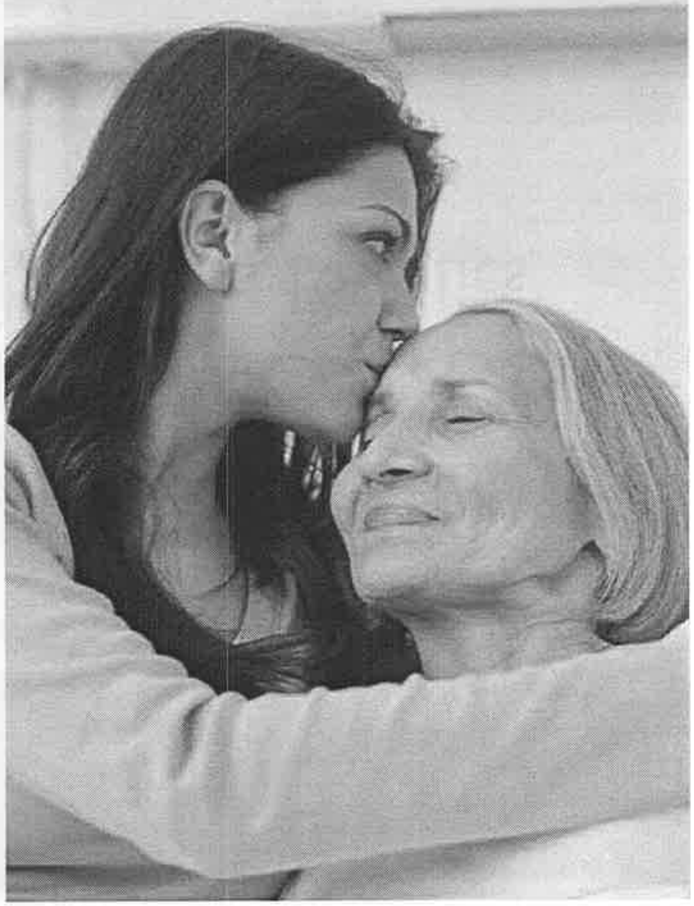
- Wear nonskid footwear
- Wear glasses (if needed)
- Change positions slowly (from lying or sitting to standing)
- Use assistive devices, such as canes or walkers, as instructed
- Ask for assistance with activities as needed

If your loved one falls, don't panic.

Notify Carroll Hospice of the fall.

If your loved one is unable to get up and you are unable to help, cover him or her with a blanket and contact Carroll Hospice for assistance.

If there is a serious injury, such as an obvious broken bone or excessive bleeding, call 911, then notify Carroll Hospice. Be sure to inform emergency medical services (EMS) staff and emergency department staff that he or she is a Carroll Hospice patient, and inform them of the Medical Orders for Life-Sustaining Treatment (MOLST) form. Take the MOLST form with you to the Emergency Department.



Spiritual Care Brochure

CARROLL
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Serving patients in Baltimore,
Carroll and Frederick Counties.

292 Stoner Avenue
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(410) 871-8000
(888) 224-2580
(410) 871-7186 TTY
(410) 871-7242 Fax
Chaplains: 410-871-7234
www.CarrollHospice.org

8/15

Spiritual Care

CARROLL
HOSPICE

A Special Kind of Caring

The spiritual care team at Carroll Hospice welcomes you.

At Carroll Hospice, your spiritual health and well-being are very important to us. We respect all faith traditions and provide spiritual care to all people who request our services. Our purpose is to provide comfort and support to our patients, their families and loved ones by offering a variety of services.

Our chaplaincy services include:

- Visitations
- Referral to other spiritual leaders
- Religious rites and services
- Prayers and commendation at the time of death
- Funeral or memorial services
- Bereavement support
- Inclusive worship (held the fourth Tuesday of every month in the Dove House chapel; please call for worship time)
- Religious literature from different faith traditions

How do I contact a chaplain?

You may call the chaplain's office directly at 410-871-7234 during the day, Monday through Friday, or at 410-871-8000 during the evenings and on weekends. You may also inform a nurse or social worker that you wish to see a chaplain and he or she will contact one. If you want someone of your religious affiliation to be notified of your admission, please call 410-871-7234.

When is a chaplain available?

A chaplain is available 24 hours a day for patients, families, visitors and staff.

Who are the chaplains?

There are three staff chaplains and several trained volunteer chaplains.

Are there chaplains available for all faiths?

Our chaplains have contacts in most faith communities and will endeavor to meet your spiritual needs. If you have a specific denomination or religious preferences you follow and want a chaplain of that faith, please make your desires known to a chaplain on site or to staff.

Is there a chapel in the Dove House?

An interfaith chapel is located in the Bereavement Center and is open 24 hours a day, every day of the week.

Exhibit 17

Caregivers

(Question 7)

When you are Grieving Brochure

Bereavement Support Services Rack Card

Bereavement Support Services Brochure

When you are Grieving Brochure

When You Are Grieving

A GUIDE TO UNDERSTANDING LOSS

Carroll
Hospice

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Although it's difficult to see
beyond the sorrow, may looking back
in memory help comfort you today.

Introduction

Life is a series of beginnings and endings. The world is filled with change, both positive and negative. Changes are often accompanied by loss and may involve grief. But no loss hits as hard as the death of someone you love.

How long you have known the person, how meaningfully and closely your lives have been intertwined, how unexpectedly he or she has died will all affect the depth of your grief and your feelings of loss.

When a family member or close friend dies, your life changes in profound and absolute ways. Nothing is the same. The world is different from this point forward. How will you ever go on? What do you do now? Can you survive?

Fortunately, we are survivors. Though it may seem unlikely at the start of mourning that life can ever be good again, it will be. As time passes, grief will lead to healing as you find renewed meaning in life and learn to embrace your loved one's memory as part of your new world.

This booklet will serve as a resource to help you begin to understand your grief, find comfort, and move forward with hope.

When someone you
love becomes a memory, the memory
becomes a treasure.

How Grief Feels

After your loss, you may feel some or all of the symptoms of grief, listed below. These feelings may come and go and vary in intensity.

- Shortness of breath
- Irregular heartbeat
- Loss of appetite
- Physical aches and pains
- Sleep disruption (too much or too little)
- Sense of heaviness, as if you are carrying a burden
- Lack of energy
- Disorientation
- Short-term memory loss
- Difficulty concentrating
- Sense that the world has become "unreal"
- Disconnection from people and life
- Lack of interest in social activities
- Feelings of sadness, anger, loneliness, guilt, anxiety

Grief can make you physically ill. If it does, you should not hesitate to seek medical assistance from your physician.

What you can do:

- Take it one moment at a time, one hour at a time, one day at a time.
- Try to maintain a normal routine.
- Get enough sleep or at least enough rest.
- Exercise regularly to relieve stress and tension.
- Eat a balanced diet. Drink plenty of water.
- If possible, postpone making major decisions, like selling your home or changing jobs, until after the first year of grieving.
- Find creative outlets to express your feelings, such as a journal, art, photography, needlework, or scrapbooking.
- Write a letter to your loved one telling him or her how you feel.

- Honor the memory of your loved one by engaging in an activity or project he or she held dear.
- Start a new family tradition in your loved one's memory.
- Think about other times you have experienced a loss and the coping skills used to survive that loss.
- Allow yourself to feel all feelings – sadness, anger, guilt, helplessness, pain.
- Cry as much as you want to. Tears help release pain and tension.
- Forgive yourself for real and imagined transgressions or missed opportunities.
- Be patient with your grief. Don't let others hurry you through your grief or tell you how you should feel.
- Attend a support group or talk to others who have lost a loved one.
- Seek out your most trusted friends or family for support when you need it. Choose to spend time with those who comfort, sustain, and recharge you.
- Accept the assistance of your close friends when they offer help. Don't go it alone.
- Take a break from your grief and do something fun – try to keep your sense of humor. See a movie, read a book, listen to your favorite music, buy a new album, get a massage.
- Above all else, **take care of yourself.**

Hope is grief's best music.

Bereavement, Grief, and Mourning

While these words are used interchangeably, they have different meanings. Knowing how each relates to loss will help broaden your understanding of what it means to be a survivor.

BEREAVEMENT is an objective fact. It is the event of loss. You are bereaved when a person close to you dies. Bereavement is also a change in status. A child becomes an orphan, a wife a widow, a husband a widower.

GRIEF is a response to the loss. It is a process. It is how survivors feel, think, and make it through the day. It is not a word that can be taken as a simple explanation of what is experienced and why. Grief permeates all aspects of life.

MOURNING is the expression of a bereaved person's thoughts and feelings. It describes the process by which a bereaved person integrates the loss into ongoing life.

Grief and mourning are the natural pathways toward coping with bereavement.

The Progression of Grief

Grief is challenging, difficult, and at times exhausting. You will grieve in an individual and personal way. There is no pattern to follow, timetable to adhere to, or model to measure yourself against. You own your grief, and what feels right to you is the right thing to do.

Some days you may feel that you are doing well, only to wake up the next morning and seemingly start the process from square one again. The goal is not to *get over* grief, but to live with it and to figure out a way to incorporate the loss into living and to keep your loved one alive in your memory.

There is no timetable for grieving.
Only you know how much time
you need to grieve.

Though there is no roadmap, there are some generalities that may be helpful to understand:

INITIAL GRIEF PERIOD. During the first few hours or days following the death, you may experience numbness, shock, and disbelief, particularly if the death was sudden or unexpected.

During this initial period of grief, you may feel confused, disoriented, and disorganized. You may feel overwhelmed and helpless. At this time, there may be decisions and arrangements to make and affairs to sort out. Family and friends gather and provide support.

MIDDLE GRIEF PERIOD. Once friends and family go back to their routine lives, you may feel anxiety, despair, and the deep pain of separation. You may feel rage and resentment and relive your loved one's last days or hours, second-guessing decisions you have made.

This period of grief, which may last for months or more, can be painful. You may experience deep sadness, longing, and loneliness. You may engage in "what-if" and "if-only" thinking that enhances the pain. As time passes, friends who were attentive at the time of death may back away.

RESOLUTION PERIOD. Eventually, you will arrive at a place where you will recognize that your life is profoundly and permanently changed, but that you are able to look positively to the future.

The heaviest burden of grief has been lifted and you will have achieved a sense of recovery and resolution. The earlier turmoil has lessened and grief has begun to recede into the background.

Reawakened Grief

Even long after a loss, you may be reminded of the death of your loved one and feel grief returning, sometimes when least expected. Common grief triggers for many people are special occasions and holidays. The anticipation of a special event may cause anxiety and fear well in advance of the actual day.

Take into account other occasions that may bring back grief reactions. A birthday, the wedding of a family member, or the birth of a grandchild may trigger grief because this would have been a family event you shared with your loved one.

What you can do:

- Prepare yourself. Recognize that a special day may be difficult, and plan ahead. Invite friends or family to be with you, if you wish, or clear your schedule for a reflective day alone.
- Plan a distraction, like going to a movie or to dinner.
- Reminisce about your loved one with family or friends, focusing on the positive memories and the times you shared.
- Initiate a ritual that you will practice on the anniversary of the loss, something that will bring meaning and comfort. Light a candle or get the photo album and reminisce. Visit one of his or her favorite places, plant a tree, or make a donation to charity.
- Find ways to incorporate the memory of your loved one on other significant days. For example, on your loved one's birthday, you could watch his or her favorite movie. If the occasion is a wedding, the bride or groom might carry something that belonged to the loved one.
- Make these rituals new family traditions to celebrate your loved one's life for years to come.

What About the Children?

If children are sharing your grief, you should help them, even though it is hard to comfort others when you are in the midst of your own grieving. Many times children are ignored because adults want to protect them and shield them from death or adults are too upset themselves to consider what children are experiencing.

Adults may think children are too young to understand what is going on and are too young to remember the loss. Even under the age of three, however, children feel loss. They sense that routines are disrupted, adults are sad, and someone they love is missing. Very young children may not comprehend death, but they understand sadness.

When a death occurs, children watch from the sidelines, not knowing how to participate and feeling abandoned.

What you can do:

- Be honest when speaking about death. Be careful of euphemisms – indirect words or phrases – that will confuse a child. For example, avoid telling a child that their loved one is "sleeping." This may make a child afraid to go to bed.
- Let the child talk, and actively listen. Encourage the child to ask questions, and answer them directly. Children will sense when you are hiding something and will back away from you at the time when they need you the most. Reassure the child that he or she is loved and cared for.
- Talk about the loved one who has died. These conversations can be therapeutic and reinforce the healing power of memories. Involve the child in rituals and ceremonies, where appropriate, so the child doesn't feel ignored.
- Don't hide your own feelings. It is healthy to grieve, and it's important for a child to understand this. Recognize that children experience many of the same feelings of grief as adults and may be angry or in denial. Acknowledge and share these feelings.
- Encourage the child to express feelings through artwork, play, and storytelling. Asking a child to describe a picture he or she has drawn is an effective way to begin a discussion.
- Contact your child's school to inform the principal, teachers, and after-school staff of the loss and ask them to help identify changes in grades, behavior, etc. Teachers and counselors appreciate this information and can be a great source of support.
- Check the school or your outreach community for availability of counseling and support groups. Peer support from shared loss provides a rich resource for grieving children because they learn from others to identify their own struggles.

Grieving Teens

Teens are often the most neglected when there is a loss because adults assume teens are old enough to handle grief themselves. This assumption often leaves teens without a source of comfort or an outlet for their feelings and fears. Even independent teenagers distancing themselves from adults need adult support in dealing with loss.

Teens may try to ignore their grief and act as if everything is normal. They may not want to upset parents, or seem childish and dependent. Regardless, teenagers need someone to talk to and also need reassurance that they are loved and cared for.

What you can do:

- Teens may experience severe mood swings, switching from extreme periods of sadness to anger and withdrawal. Validate all emotions and avoid minimizing their pain.
- Approach your teen thoughtfully, being cautious not to overwhelm or smother them. Teens may isolate themselves from adults and seek solace with their peers, or they may change peer groups. Peers may not be a source of true comfort unless they, too, have been through the grief process.
- Encourage teens to use journaling, art, music, and other forms of personal expression to help relieve the stress of mourning. Support groups can be beneficial, helping teens to normalize their experiences.
- Teens may act out feelings by doing poorly in school, fighting, abusing alcohol or drugs, or becoming defiant or promiscuous. Again, ask school staff to help identify changes in behavior. Seek guidance from a therapist experienced in working with teens if negative behaviors become out of control.

Final Thoughts

As you journey through your grief, remember that there are numerous resources that can help you. Explore what your community has to offer, such as support groups and counselors. Many community organizations offer free grief support groups. There are books for adults, teens, and children on every aspect of grief and loss and websites that provide a wealth of information.

Grief is a process, not an event.
Be gentle with yourself as you journey
along that sacred path known as grief.

Provided by

Carroll Hospice

292 Stoner Avenue
Westminster, MD 21157

Telephone: (410) 871-8000
Fax: (410) 871-7242

www.carrollhospice.org

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Bereavement Support Services Rack Card

Bereavement Support Services

Carroll Hospice offers support services and bereavement resources to families, friends and community members grieving the loss of a loved one, pet or significant person in their lives. Skilled, caring and certified counselors lead the programs, assisted by trained volunteers in grief and loss. All programs are held at Carroll Hospice, 292 Stoner Avenue, Westminster, unless otherwise noted.

Pathways Support Group

Open to any adult who has experienced the death of a loved one. The group addresses the emotional issues surrounding the loss and offers coping strategies. Third Wednesday of each month, 6:30 – 8 p.m. No registration required.

Bereavement Luncheons

An opportunity to meet, have lunch and receive support from others in the community who are grieving the death of someone close. Last Tuesday of each month, noon, Baugher's Restaurant, 289 West Main Street, Westminster. No registration required.

Widows and Widowers Support Group

Open to women and men of all ages who have experienced the death of a spouse or partner. Attendees receive emotional support and discuss techniques to successfully cope with their grief in a friendly and nurturing environment. First Tuesday of each month, 6:30 – 8 p.m. No registration required.

Grief after a Substance Abuse Loss Support Group

Open to those who have experienced the death of a loved one related to substance abuse or addictions. The group addresses the unique emotional issues surrounding the loss and offers coping strategies. First Tuesday of each month, 5 – 6:30 p.m. No registration required.

Continued on reverse ►

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Affiliated with Carroll Hospital,
a LifeBridge Health center

Mending Hearts

Open to those who have experienced the death of a child. This group addresses emotional issues surrounding the loss and offers coping strategies. Third Monday of each month, 6:30 – 8 p.m. No registration required.

Pet Loss Support Group

This support group offers people of all ages whose pets have died the opportunity to share their feelings and receive emotional support from others facing a similar loss. Quarterly on a Saturday, 10:30 a.m. – noon. Call for dates; registration required.

Camp T.R.

A weekend grief camp for children (ages 7–15) who have experienced the death of a loved one. Each participant is assigned a grief buddy who is specially trained in helping grieving children. Held first weekend in June at Hashawha Environmental Center, 300 John Owings Road, Westminster. Registration and completed application required.

Bereavement support groups are open to anyone in the community regardless of where the death occurred. If the weather is inclement, please follow Carroll County Public Schools policy. If schools are closed, our groups are canceled.

To register for a program or for more information, please call Carroll Hospice at 410-871-7656.

292 Stoner Avenue • Westminster, MD 21157

1-17

Bereavement Support Services Brochure

About Carroll Hospice

An affiliate of Carroll Hospital Center, Carroll Hospice provides high quality, patient-centered care to terminally ill individuals and their loved ones. Through specialized nursing services, along with spiritual and emotional support, Carroll Hospice helps patients live out the remainder of their days in dignity, in the warmth and familiarity of their own home, a health care setting or our beautiful inpatient facility, Dove House. For grieving family members, Carroll Hospice offers a host of resources, including bereavement counselors, a comprehensive bereavement center with resource library (located in Dove House) and support groups for all ages.

To learn more. . .

For information about Carroll Hospice's bereavement programs and resources, including support group schedules and counseling appointments, call 410-871-7656.

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An affiliate of Carroll Hospital Center

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11/14

Bereavement Support

Carroll Hospice

A Special Kind of Caring

Compassionate support for the road ahead...

Grief is a natural reaction to the loss of a loved one. Highly personal and complex, it affects each person differently. Above all, grieving family members and friends should remember that they have a right to mourn their loved one in their own way and at their own pace.

Carroll Hospice helps individuals to better understand and cope with their grief, while respecting their unique grieving style. For at least 13 months after the death of a Carroll Hospice patient, our experienced grief counselors and specially trained volunteers provide compassionate support to the patient's family members and close friends. We also offer bereavement services to community members (adults and children)grieving a sudden, unexpected loss.

Resource-rich bereavement center

Carroll Hospice's inpatient hospice facility features a comfortable bereavement center that includes a library filled with resources on hospice and the grieving process. Each weekday, the center is staffed by a full-time bereavement counselor who can meet with visitors or help them locate specific library resources.

Individual counseling

For those who prefer one-on-one support, our experienced bereavement counselors and chaplains are available to listen and help you on your grieving journey. This service is offered to those served by Carroll Hospice and those in the community who have lost a loved one.

A variety of support groups

Many grieving individuals find strength, healing and understanding through support groups. Carroll Hospice offers a broad selection of support groups for children and adults at no cost. Though settings and formats vary, each group provides a safe, supportive atmosphere where participants can share experiences, coping strategies, emotions and information.

For more details about any of our support groups, including locations and meeting times, or to register, please call 410-871-7656.

Our support groups are open to the community and include:

For Adults

- *Pathways* – This monthly support group helps participants address the emotional issues surrounding their loss and adopt helpful coping strategies. No registration required.
- *Bereavement Luncheons* – An opportunity to connect with other grieving community members over lunch. Offered monthly. No registration required.
- *Widowers Support Group* – A monthly bereavement support group open to men of all ages whose spouse has died. This group addresses emotional issues regarding loss unique to men and offers coping strategies. No registration required.
- *Widows Support Group* – A monthly support group for women whose spouse has died. The group addresses emotional issues surrounding the loss of a spouse and offers coping strategies. No registration required.
- *Pet Loss Support Group* – This quarterly support group is for anyone who has lost a pet and addresses the emotional issues surrounding the loss and provides coping strategies.

For Children

- *Camp T.R.* – A weekend retreat for grieving children ages 7 through 15. The annual camp combines recreational activities such as art, swimming and music with grief education and support. Application required.
- *Healing Hearts Day Camp* – A bereavement day camp for children ages 7 through 13. This annual camp provides opportunities for children to learn ways of coping with loss through a combination of activities and quiet sharing and support. Application required.

Community Education

- *Bereavement Skills Training* – A series of educational classes for anyone interested in training in bereavement and grief issues. Suitable for those interested in becoming grief companions for Carroll Hospice or professionals including teachers, counselors, nurses and pastors seeking additional training and skills. Registration required.

Exhibit 18

Information for Providers & the General Public

(Question 9)

Carroll Hospice: A Special Kind of Caring,
General Brochure

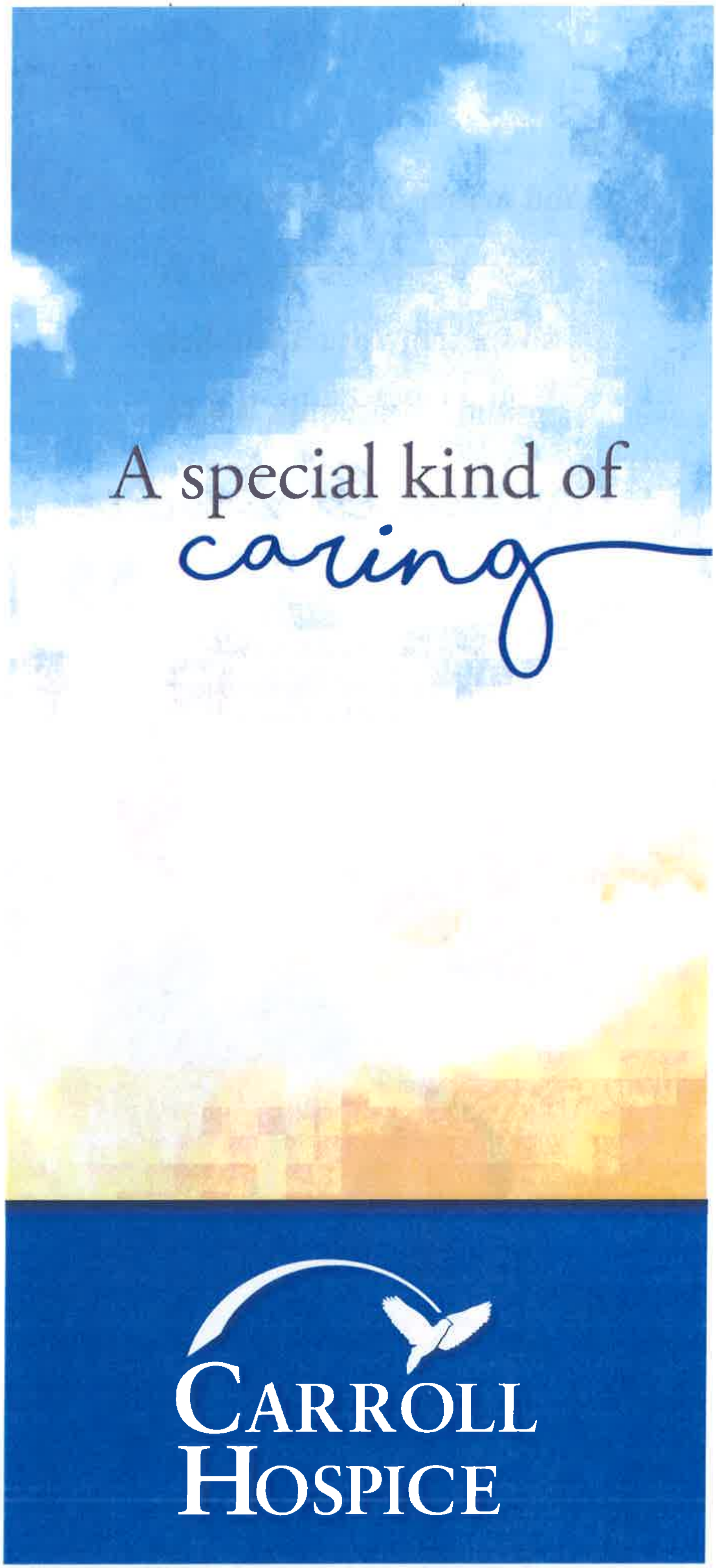
Carroll Hospice Information and Stats Sheet

Right Care at the Right Time Power Point
Presentation

Camp TR, Retreat for Children, Rack Card

Visit Carroll Hospice Online Rack Card

Carroll Hospice: A Special Kind of Caring, General Brochure



A special kind of *caring*

CARROLL
HOSPICE

> “You matter to the last moment
> of your life, and we will do
> all we can, not only to help
> you die peacefully, but to
> *live until you die.*”

Dame Cicely Saunders, 1968
FOUNDER OF THE FIRST MODERN HOSPICE
LONDON, ENGLAND

What is hospice?

Hospice is a patient-centered, family-oriented approach to care for anyone in the advanced stages of a life-limiting illness. By combining careful pain and symptom management with spiritual and emotional support, hospice enables patients to live out the remainder of their days in comfort and dignity, surrounded by those they love. Hospice care neither hastens death nor prolongs life, but allows the illness to take its natural course.

For families, hospice provides extensive bereavement support, both before and after the loss of a loved one.

our philosophy

- Provide patients with palliative care and effective pain and symptom management
- Help patients experience peace, comfort and dignity through the end of life
- Allow patients to make their own decisions regarding care and treatment
- Promote a caring community sensitive to the needs of hospice patients and their families
- Support family members and other caregivers in their efforts to care for their loved one
- Coordinate community resources to ensure continuity of care
- Offer bereavement support to families and the community

About Carroll Hospice

Carroll Hospice is dedicated to ensuring the quality of life for patients through end-of-life care. Our holistic philosophy of treatment addresses patients' physical, emotional and spiritual needs, allowing them to live as fully and comfortably as possible. Whether caring for patients in their own homes, in health care settings such as nursing homes or in our beautiful inpatient facility, we help patients make the most of each day while respecting their end-of-life wishes.

Carroll Hospice serves patients in Baltimore, Carroll and Frederick counties. We are Medicare certified, licensed by the State of Maryland and accredited by the Community Health Accreditation Program (CHAP). We also are a member of the Hospice and Palliative Care Network of Maryland and the National Hospice and Palliative Care Organization.

Where do patients receive hospice care?

Most hospice care is provided in the patient's choice of residence, including a private home, a nursing facility or an assisted living community. This allows patients to receive the care they need in a familiar setting. Home hospice care support is available 24 hours a day, seven days a week. If an immediate need arises, an on-call nurse is available to address the concern.

A home away from home: Dove House

Some patients require a level of care that cannot be provided in their current residence. In these instances, Carroll Hospice's beautiful, homelike inpatient facility—Dove House—offers a warm, supportive environment that provides high quality care 24 hours a day from an expert team of professionals and volunteers dedicated to helping them live comfortably.

Patient amenities

Each patient room at Dove House is specially designed to mirror the comforts of home and features a host of amenities, including:

- Veranda or porch, most with beautiful views of the Carroll County landscape
- Homelike beds that can be easily rolled out onto the veranda or porch
- Daybed with pullout sleeper for family members
- Armoire with television
- Private bathroom

Amenities for families and visitors

At Dove House, we promote relationships with families, caregivers and loved ones, just as we do when caring for a patient at home. In fact, family and friends are encouraged to visit any time and may stay overnight if they wish.

Amenities include:

- Large, open living room for gathering and entertaining
- Dining room for family meals with light refreshments available
- Family room with kids' corner, filled with toys, books and games
- Nondenominational chapel and memorial garden
- Bereavement resource center staffed by grief counselors

Who provides hospice care?

Care is provided by our team of registered nurses, certified hospice aides, physicians, social workers, bereavement counselors, chaplains and volunteers. Team members work closely with each patient to provide effective pain and symptom management that respects his or her unique care and treatment preferences. Our on-call hospice team is available around the clock, seven days a week.

The physician's role in hospice care

The patient's primary care physician works with the hospice medical director and interdisciplinary team to develop a plan of care to ensure the patient's end-of-life needs are met.

How does Carroll Hospice help families?

While their loved one is enrolled in Carroll Hospice, we assist family members with day-to-day caregiving responsibilities and offer respite care—a short break for the responsibilities of caregiving.

We also provide bereavement support for at least 13 months following the death of a patient. Individual and group counseling for adults and children is available, along with a resource-filled bereavement center. Carroll Hospice's grief support groups and programs include:

- Pathways – monthly support group for adults grieving the loss of a loved one.
- Widowers Support Group – monthly group open to men of all ages who have lost a loved one.
- Widows Support Group – monthly group open to women of all ages whose spouse has died.
- Camp T.R. – a weekend retreat for children ages 7 through 15. The annual camp combines recreational activities, such as art, swimming and music, with grief education and support.

For a full list of ongoing support groups, please visit CarrollHospice.org.

When should hospice be contacted?

Hospice care is appropriate when patients and those who love them are in agreement with a palliative, comfort-oriented approach to care. Earlier referral to the hospice program allows the hospice team to fully understand what is important to the patient and tailor the plan of care to meet his or her unique needs.

Criteria for admission:

- Patient has a confirmed diagnosis of a life-limiting illness with a prognosis of six months or less
- Physician and patient have determined that curative therapy is no longer available or desired
- Patient, family and physician are aware of prognosis and agree with a comfort-oriented approach to care

If you are unsure whether you or your loved one is ready for hospice care, contact Carroll Hospice directly at 410-871-8000.

Who pays for hospice care?

While Carroll Hospice cares for all patients regardless of their ability to pay, Medicare, Medicaid and other medical assistance programs provide coverage for hospice services. Most commercial and private insurance companies offer a hospice benefit as well.

How can community members support Carroll Hospice?

Carroll Hospice pledges to care for all patients, regardless of their financial situation. To do this, we rely on the support of many generous organizations and individuals. You can support Carroll Hospice financially through the following:

- Gifts to Carroll Hospice
- In-kind contributions
- Memorial contributions
- Bequests
- Monetary gifts

To make a donation to Carroll Hospice, call 410-871-7233 or visit CarrollHospice.org.

What about volunteer opportunities?

Carroll Hospice volunteers play a key role in our mission to provide patients with a dignified, comforting system of care during their final days. While some of our volunteers have professional skills or specialized expertise, most are people who want to help their friends and neighbors and serve the community.

Volunteers serve Carroll Hospice in a variety of capacities, such as providing companionship and respite care, organizing and supporting fundraising and outreach events, assisting with administrative tasks and serving as a camper "buddy" at Camp T.R., our weekend retreat for grieving children.

To learn more about Carroll Hospice volunteer opportunities, call 410-871-7228.

visit us online

CarrollHospice.org

- Access grief resources
- View our calendar of events
- Download newsletters and brochures
- Make a referral for hospice care
- Donate online

Frequently asked questions

Is hospice care only for the elderly?

Hospice care is available to people of all ages, including children who have been diagnosed with a progressive or life-limiting illness.

Who decides if hospice care is needed?

Together, the physician, patient and family determine when hospice care is needed and what services are necessary. A patient can receive hospice care when a life-limiting illness is present, and life expectancy is six months or less if the disease follows its normal course.

What is Carroll Hospice's service area?

We serve patients residing in Baltimore, Carroll and Frederick counties.

What if a patient cannot receive care at home?

Our skilled social workers will assist patients and their families if alternative caregiving or living arrangements need to be made.

For patients requiring symptom management, Carroll Hospice's inpatient hospice facility, Dove House, is available.

To learn more or to take a tour, call 410-871-8000.

Can Carroll Hospice patients continue to see their primary care physician?

Yes. The patient's primary care physician works closely with the hospice medical director and interdisciplinary team to develop a plan of care that ensures the patient's end-of-life preferences are met.

What if a patient's condition improves after he or she enters hospice?

If a patient improves while in hospice care, the hospice team works closely with the patient, family and physician to create a plan for discharge and ongoing care.

to learn more

Visit CarrollHospice.org or
call 410-871-8000.
From Baltimore: 410-876-8044
TTY users: 410-871-7186

Dove House (Inpatient Hospice):
410-871-7528 or 1-877-867-7794

Services are provided regardless of race, gender, age, religion, national origin, disability, marital status or ability to pay.

CARROLL HOSPICE

Home hospice | Inpatient hospice | Bereavement support
Serving Carroll, Baltimore & Frederick counties

A non-profit affiliate of Carroll Hospital, a LifeBridge Health center

292 Stoner Avenue
Westminster, Maryland 21157
410-871-8000 | 888-224-2580
410-876-8044 from Baltimore
410-871-7186 TTY | 410-871-7242 Fax
CarrollHospice.org

WE HONOR VETERANS

CHAP

2/16

Carroll Hospice Information and Stats Sheet

CARROLL
HOSPICE

Info & Stats

A private, nonprofit organization affiliated with Carroll Hospital, a LifeBridge Health center, serving people with life-limiting, progressive illnesses in Carroll, Frederick and Baltimore counties for 30 years

FY 2016 Statistics

(see reverse for more information)

Patients Admitted	910
Average Daily Census *(as of 12/16)*	122
Number of Employees	80
Number of Volunteers	174
Total Volunteer Hours	9,828

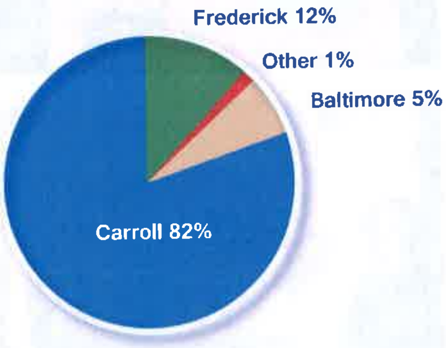
Services

- **Interdisciplinary Team**
  - Medical Director
  - R.N. Case Manager
  - Licensed Social Worker
  - Chaplain
  - Certified Hospice Aide
  - Volunteer Support
- **Dove House Inpatient Facility (8 beds)**
- **Home Hospice Care at private residences or continuing care facilities**
- **VA Partnership – We Honor Veterans**
  - Veteran Patients Served: 173 (Equals 19% of Total Patients Served)
- **Patient Family and Community Bereavement Support**
  - Patient family members served in 2016: 1,098
  - Community members served in 2016: 2,732
  - Grief Support After A Substance Abuse Loss Support Group
  - Mending Hearts Support Group
    (for those experiencing the loss of a child at any age)
  - Camp T.R. Children's Weekend Grief Retreat
    (helping 18 to 20 children annually)
- **Therapeutic Services**
  - Pet therapy
  - Acupuncture
  - Reiki

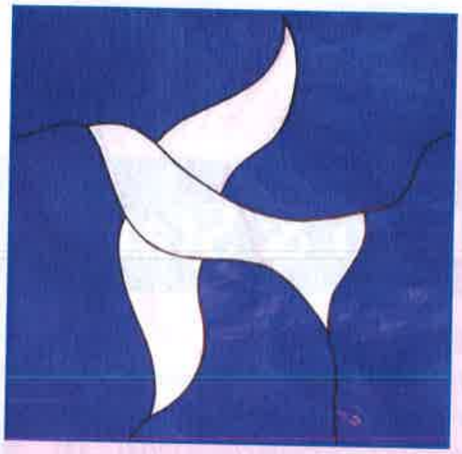
Counties We Serve

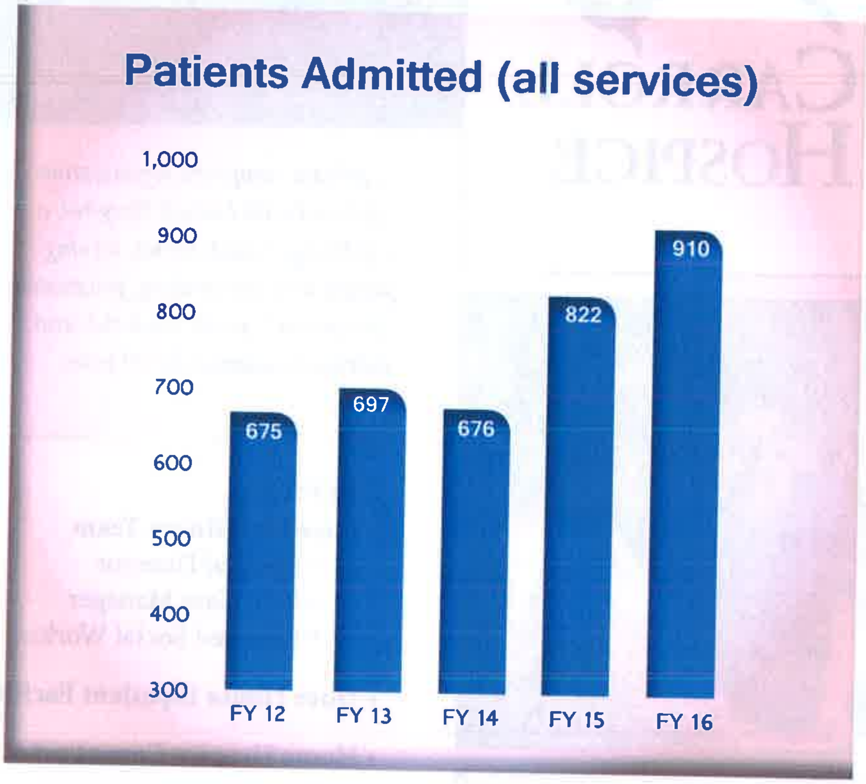
FY16 Admissions (910 total)

Carroll County (745)	82%
Frederick County (109)	12%
Baltimore County (45)	5%
Other (11)	1%
	100%

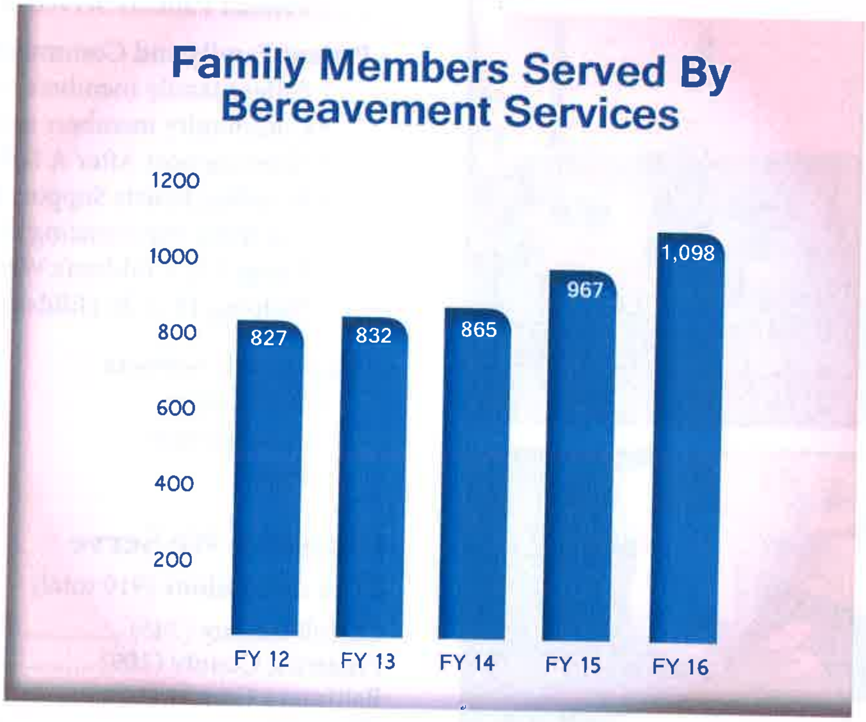


292 Stoner Avenue • Westminster, MD 21157
410-871-8000 • CarrollHospice.org



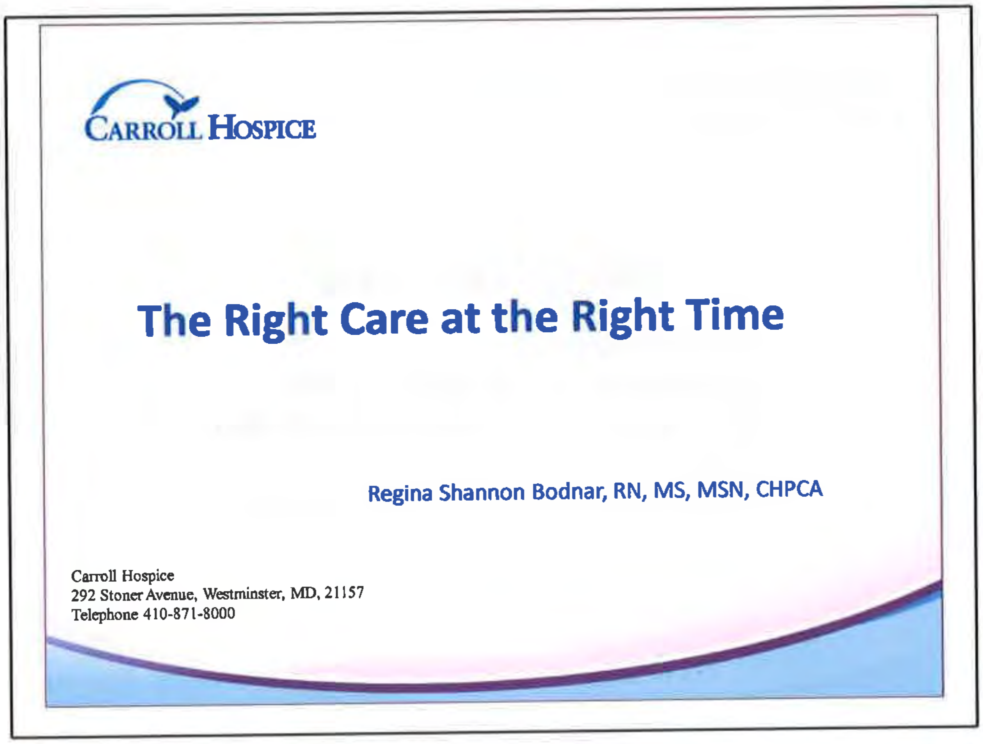


Patients Admitted (all services)



Family Members Served By Bereavement Services

Right Care at the Right Time Power Point Presentation



CARROLL HOSPICE

The Right Care at the Right Time

Regina Shannon Bodnar, RN, MS, MSN, CHPCA

Carroll Hospice
292 Stoner Avenue, Westminster, MD, 21157
Telephone 410-871-8000

CARROLL HOSPICE

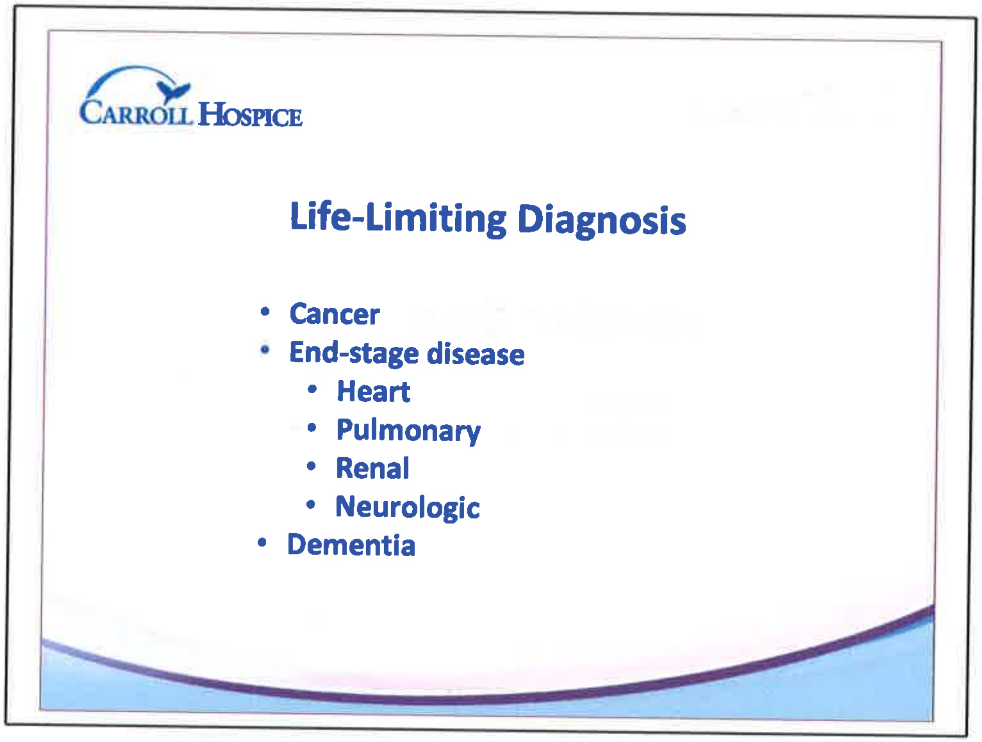
Hospice Care

- Palliative Care
- End-of-Life Care

Carroll Hospice

Hospice Care

- Life-limiting diagnosis
- Life expectancy of 6 months or less
- Philosophy of care – comfort rather than cure
- Patient and Family are the unit of care



Carroll Hospice

Life-Limiting Diagnosis

- Cancer
- End-stage disease
  - Heart
  - Pulmonary
  - Renal
  - Neurologic
- Dementia

CARROLL HOSPICE

Referrals

- Should not imply a change in status is imminent
- Can be initiated by family, facility, physician...
- Suggest the goals of care have changed and

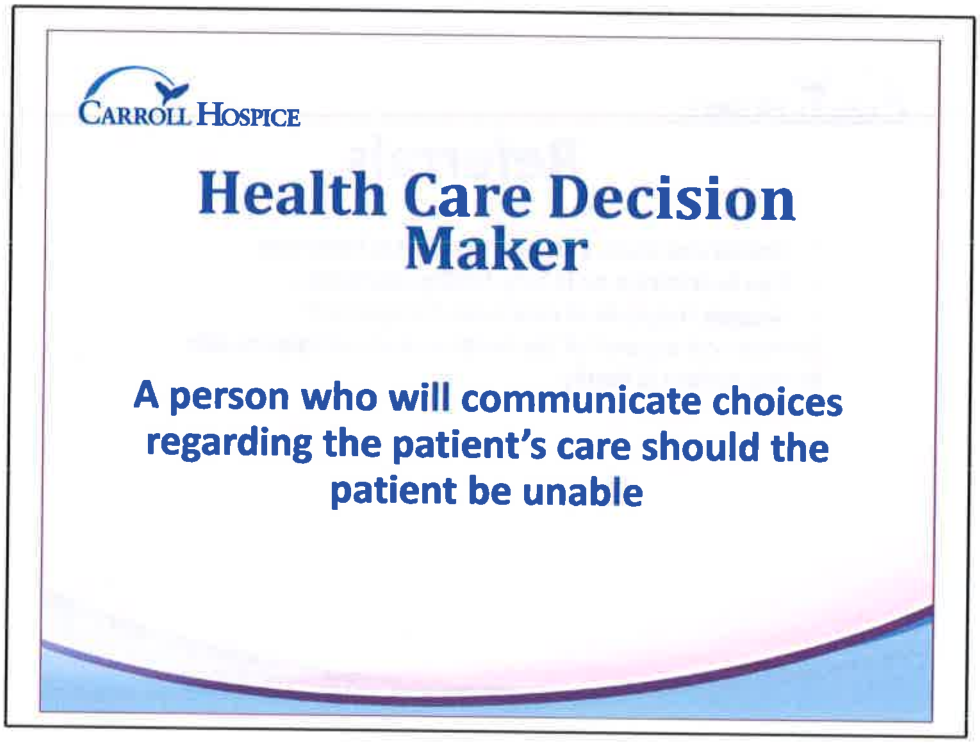
Services and support of the hospice team are appropriate for the patient & family

---

CARROLL HOSPICE

Hospice Team

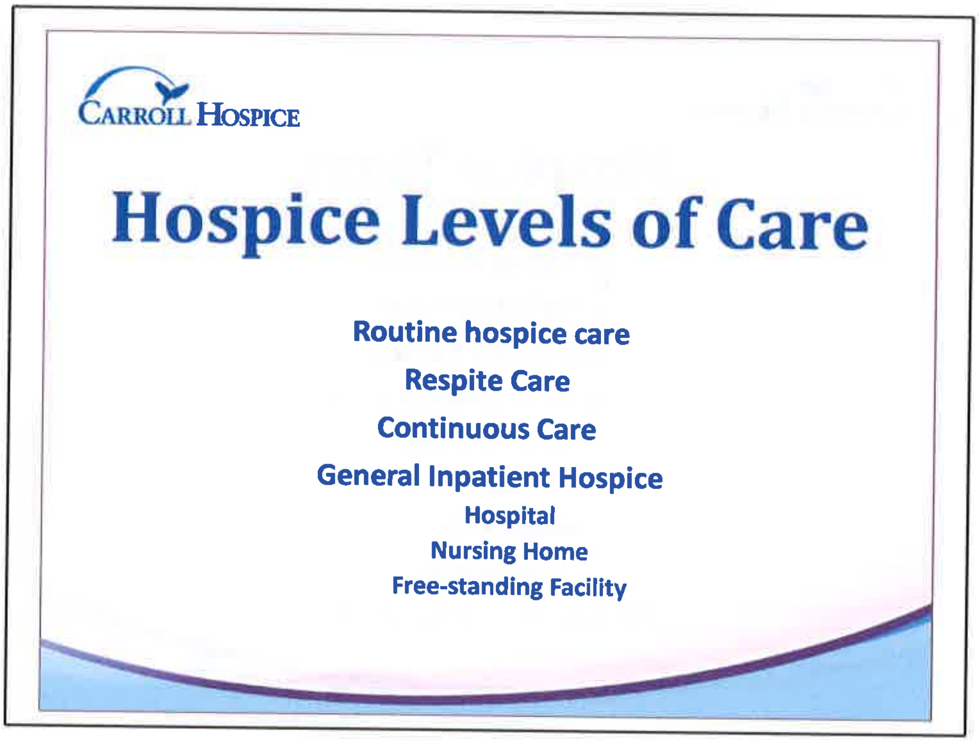
Attending Physician
Medical Director
Registered Nurses
Licensed Practical Nurses
Social Workers
Chaplains
Hospice Aides
Volunteers
Bereavement Counselors



CARROLL HOSPICE

Health Care Decision Maker

A person who will communicate choices regarding the patient's care should the patient be unable



CARROLL HOSPICE

Hospice Levels of Care

Routine hospice care

Respite Care

Continuous Care

General Inpatient Hospice
- Hospital
- Nursing Home
- Free-standing Facility

CARROLL HOSPICE

Routine Care

Care is provided by skilled intermittent visits

As disease is progressing, symptoms are managed to the patient and family's satisfaction

Care is provided in the patient's choice of residence

Private Home
Assisted Living Facility
Nursing Home
Group Home
Hospice Residence

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Facility Based – Routine Care

Special Hospice Care Team

Key component when partnering with a community of care requires:

Identification of consistent goals of care
Commitment to respectful professional relationships
Recognition and appreciations of skills, knowledge, and expertise
Communication
Collaborative energies
Hospice flexibility and acknowledgement of the uniqueness of each facility

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Respite Care

Patient's condition is stable

Family needs a break from care giving or with balancing multiple life demands

Typically up to a 5-fay benefit

Can be utilized multiple times

Requires transfer to a facility contracted with the hospice

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Continuous Care

Symptoms present which require skilled intervention

Patient/family desires to remain in choice of residence

Hospice staff remain with patient a minimum of 8 hours/day

More than one half of the care is provided by a skilled professional

CARROLL HOSPICE

Inpatient Care

Symptoms present which requires skilled intervention

Care is provided outside of the home environment

- Hospital
- Nursing Home
- Free-standing Hospice Facility

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Cost of Hospice Care

- Medicare
- Medical Assistance
- Commercial Insurance
- Uncompensated Care

CARROLL HOSPICE

Medicare Hospice Benefit

Diagnosis specific

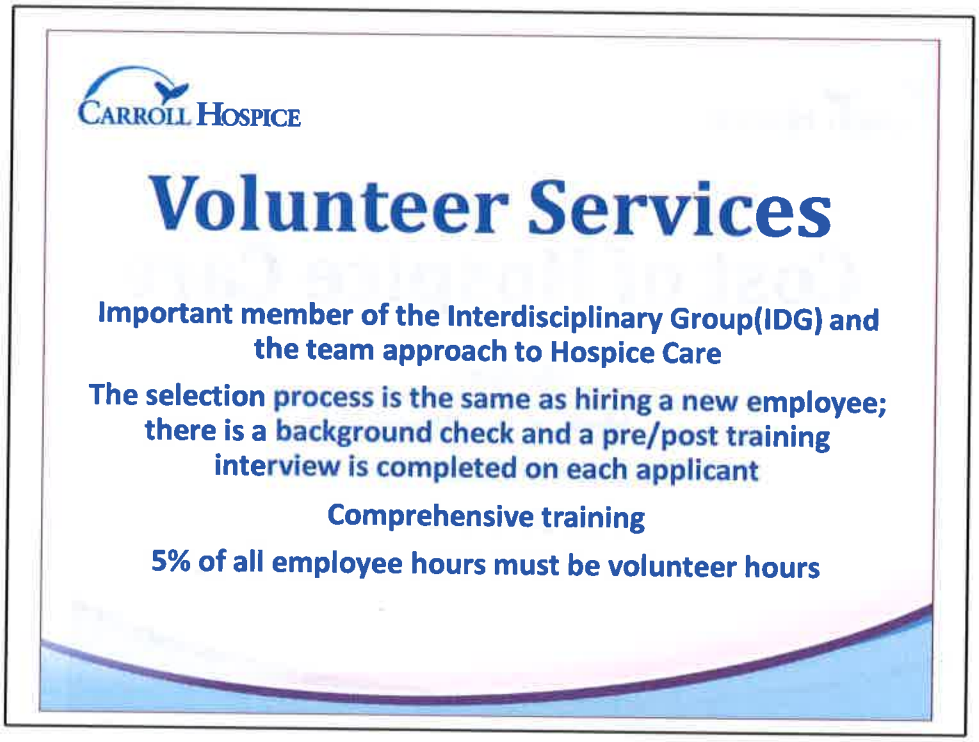
4 levels of care

Human Services – professionals and volunteers

Medications related to life limiting diagnosis

Supplies related to life limiting diagnosis

Equipment needed to assure patient's comfort and safety



CARROLL HOSPICE

Volunteer Services

Important member of the Interdisciplinary Group(IDG) and the team approach to Hospice Care

The selection process is the same as hiring a new employee; there is a background check and a pre/post training interview is completed on each applicant

Comprehensive training

5% of all employee hours must be volunteer hours

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Bereavement Services

- Counseling
- Support Groups such as:
  - Widowed Persons/Life Partners
  - Young Widowed Persons/Life Partners
  - Adult with Parental Loss
- Educational Workshops
- Bereavement Retreat
- Memorial Services

CARROLL HOSPICE

Keeping Patient Care First

- Being committed to getting it right the first time.

  There are no "*do overs*"...

  and there should be no regrets!
- Appreciate that hospice is a very human science
- Ongoing staff support and education to address the burdens of cumulative loss
- Recognize the beauty of boundaries

Camp TR, Retreat for Children, Rack Card

camp T.R.

Camp T.R. is a FREE, overnight weekend retreat for children ages 7 through 15 who are grieving the loss of a loved one.

The camp offers a safe, supportive environment to help children understand and cope with their grief. Surrounded by peers experiencing similar emotions, campers learn that they are not alone and start to feel more comfortable sharing their feelings.

What types of activities are offered?

Through creative exercises, honest discussions and recreational activities, campers learn positive ways to express their emotions and honor their loved one. In addition to grief education and support, daily activities may include:

- Arts and crafts
- Dance
- Music
- Swimming
- Hiking
- Games

CARROLL
HOSPICE

More information on other side ►

To register a child for Camp T.R. or for general information, including upcoming camp dates, call 410-871-8000 or visit CarrollHospice.org. Please register promptly; attendance is limited to 25 campers.

Who are the staff members?

Camp T.R. is staffed by professional bereavement counselors and volunteers with special training in helping grieving children. Each camper is also assigned a "buddy" (usually a volunteer) for added support.

Where do campers stay?

Campers stay in one of five secure, comfortable cabins on the grounds of the Hashawha Environmental Center in Westminster, Md. Situated on Lake Hashawha, the center gives campers a much-needed change of scenery, along with a broad range of outdoor recreational opportunities.

How can Camp T.R. help a grieving child?

The death of a family member can shatter a child's world. They might feel angry, lonely, guilty or scared, or experience physical symptoms such as headaches, stomach aches and fatigue. Oftentimes, they become the "forgotten mourners" as the adults around them struggle to cope and adjust to the loss. But children need time and space to grieve as well.

Camp T.R. provides children with a safe and therapeutic environment to grieve.

Visit Carroll Hospice Online Rack Card

Visit Carroll Hospice Online

Carroll Hospice has been serving people with life-limiting, progressive illness and their families for more than 25 years.

Our comprehensive and compassionate care addresses the patient's physical, emotional and spiritual well-being, allowing them to live as fully and comfortably as possible in their final months. We also provide support for families through our bereavement programs.

At **www.CarrollHospice.org**, learn more about hospice's services, resources and mission of caring.

Visit our website to:

- Find out how Carroll Hospice can help you and your family
- Make a referral to hospice care
- View a slideshow of Dove House, our homelike inpatient facility in Westminster
- Discover volunteer opportunities
- Learn about bereavement services for family members
- Make a donation or gift of tribute

Carroll Hospice serves Carroll, Baltimore and Frederick counties.

CHAP

12-12-12 x500

www.CarrollHospice.org

Exhibit 19

Quality

(Question 13)

QAPI Characteristics Chart

Carroll Hospice Quality Improvement and Patient Safety Plan

QAPI Characteristics Chart

QAPI Characteristic as Described by OHCQ	State regulation reference	Location/citation in Applicant's QAPI
Develop, implement and maintain an effective, ongoing, hospice-wide data driven QAPI program	10.07.21.09A & B A. The governing body shall ensure that the hospice care program conducts ongoing quality assurance and utilization review. B. Quality Assurance Program. The governing body shall assure that the hospice care program develops and implements a quality assurance and improvement program to assess and improve the quality of services being provided by the program.	Page 3 Section 2, Leadership & Organization
Maintain documentary evidence – able to demonstrate operation	10.07.21.09D(2)Maintain records to demonstrate the effectiveness of its quality assurance activities	Page 3 Section 2, Leadership & Organization
Program capable of showing measurable improvement in indicators related to improved palliative outcomes and hospice services	10.07.21.09C(2)Have outcomes and results that are measurable and which may be incorporated into systemic changes in the program's operation;	Pages 6 – 10 Executive Summary
Must measure, analyze and track quality indicators including adverse patient events	10.07.21.09C(3) Require the systematic collection, review, and evaluation of information and data and the analysis of trends identified through the quality assurance process	Page 3 Section 2, Leadership & Organization
Must use quality indicator data in design of program to: monitor effectiveness and safety of services and quality of care; identify opportunities for improvement	10.07.21.09D(3) Implement changes based upon results of the evaluated data; for example, when problems are identified in the provision of services, the hospice care program shall document corrective actions taken, including ongoing monitoring, revisions of policies and procedures, and educational interventions	Pages 6 – 7 High-Quality Outcomes
Frequency and detail of data collection must be approved by governing body	10.07.21.09E The hospice care program shall be held accountable by the governing body for accomplishing the goals and standards that are established as part of the quality assurance and improvement system.	Page 3 Section 2, Leadership & Organization

Must focus on high risk, high volume or problem prone areas		Page 3 Section 2, Leadership and Organization
PI activities must track adverse patient events, analyze their causes and implement preventive actions	10.07.21.09D(3) Implement changes based upon results of the evaluated data; for example, when problems are identified in the provision of services, the hospice care program shall document corrective actions taken, including ongoing monitoring, revisions of policies and procedures, and educational interventions	Page 5 Goals, #3 Improve Patient Safety Data Collection
Must measure success and track performance to ensure improvements are sustained		Page 2 Section 1, Continuous Quality Improvement Activities
Number and scope of PIP (performance improvement projects), conducted **annually** based on the needs of the hospice's population and internal organizational needs, must reflect the scope, complexity and past performance of the hospice's services and operations	10.07.21.09C(1-6) C. The quality assurance and improvement program shall: (1) Focus on: (a) The needs, expectations, and satisfaction of patients and their families, and (b) All services provided by the hospice care program; (2) Have outcomes and results that are measurable and which may be incorporated into systemic changes in the program's operation; (3) Require the systematic collection, review, and evaluation of information and data and the analysis of trends identified through the quality assurance process; (4) Require that regular reports are prepared and reviewed by the governing body and appropriate personnel; (5) Provide for prompt and appropriate response to incidents when the patient's health and safety is at risk; and (6) Include proactive strategies to improve the quality of services.	Pages 3 – 5 Section 3, Objectives, Goals and Performance Measurement
Governing Body- responsible for ensuring that one or more individual(s) who are responsible for operating the QAPI program are designated	10.07.21.09D(4) Identify the individual responsible for performing the quality assurance functions as set forth in this regulation	Page 3 Leadership & Organization

Carroll Hospice Quality Improvement and Patient Safety Plan

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HOSPICE

Carroll Hospice

Quality Improvement and Patient Safety Plan

FY2017

Quality Improvement and Patient Safety Plan
Carroll Hospice
FY 2017

Section 1 Introduction

Mission:

Carroll Hospice is non-profit organization dedicated to improving the quality of life for patients needing end-of-life care, allowing them to live as fully and comfortably as possible by providing quality palliative care, pain and symptom management and support for their families.

Our Philosophy

- Provide patients with palliative care and effective pain symptom management.
- Help patients experience peace, comfort and dignity during the end stage of life.
- Allow patients to make their own decisions regarding care and treatment.
- Promote a caring community sensitive to the needs of hospice patients and their families.
- Support family members and other caregivers in their efforts to care for their loved one.
- Coordinate community resources to ensure continuity of care.
- Offer bereavement support to families.

Scope of Service:

Carroll Hospice (CH) is a 501(c)3 hospice organization which has provided quality and compassionate hospice care to terminally ill patients and their families in Carroll County and the surrounding areas for thirty years. CH opened its doors in 1986 and has since expanded to serve more than 100 terminally-ill residents of Carroll, Frederick and Baltimore counties each year in their homes, independent living facilities, long term care residences and the Dove House inpatient unit.

In 2016, the Dove House inpatient unit became dually licensed as a Hospice House through the state of Maryland and has since been able to offer residential care in addition to general inpatient and inpatient respite levels of care.

CH is an affiliate of Carroll Hospital, which became a LifeBridge Health center in 2015. The CH Quality Improvement and Patient Safety Plan has been designed to address all stakeholders, including Carroll Hospital and the LifeBridge Health team, and in consideration of the culture of safety among the CH community. The plan will address the SPIRIT values, including Service, Performance, Innovation, Respect, Integrity and Teamwork. The scope of the Quality Improvement and Patient Safety Plan includes all paid and unpaid staff, including contractual staff not employed by the organization.

Continuous Quality Improvement Activities

CH and Carroll Hospital subscribe to Lean management principles of continuous performance improvement to track performance and ensure improvements are sustained. Performance Improvement Projects will be modeled after the institute for Healthcare Improvement's Plan-Do-Study-Act (PDSA) Model for Improvement.

Section 2 Leadership and Organization

The CH ***Quality Assessment Performance Improvement Committee*** provides ongoing operational leadership of continuous quality improvement activities. The QAPI Committee meets quarterly and is chaired by the Accreditation and Quality Specialist. The activities of the QAPI Committee serve to implement and maintain an effective, ongoing, hospice-wide data driven QAPI program.

The responsibilities of the Committee include:

- Developing and approving the Quality Assessment Performance Improvement Plan on at least an annual basis.
- Establishing measurable goals based upon problem prone, high risk or high volume areas of hospice care services.
- Developing indicators of quality on a priority basis.
- Ongoing evaluation of information based on indicators, taking action as evidenced through quality improvement initiatives to solve problems and pursue opportunities to improve quality.
- Establishing and supporting specific quality improvement initiatives through the Lean principles of continuous performance.
- Maintaining documentary evidence of QAPI activities.
- Reporting to the Board of Directors on quality improvement activities at least on an annual basis.
- Communication of QAPI activities to the Leadership Team, staff and families as appropriate.

The ***Board of Directors*** also provides leadership for the Quality Improvement process as follows:

- Reviewing, evaluating and approving the Quality Improvement Plan annually.
- Supporting implementation of quality improvement activities.

The Leadership Team supports QAPI activities through the planned coordination and communication of the results of measurement activities related to QI initiatives and overall efforts to continually improve the quality of care provided. It is a function of the Leadership Team to ensure that the Board of Directors have knowledge of and input into ongoing QAPI initiatives.

Section 3 Objectives, Goals and Performance Measurement

The QAPI Committee identifies and defines goals and specific objectives to be accomplished each year in consideration of the current regulatory climate, completed or continued QAPI and Lean projects, organizational committee work, accreditation survey results and the scope, complexity and past performance of Carroll Hospice service and operations.

Objectives

The overarching quality strategy for FY2017 is to:

- Build a system in which high quality outcomes are the only option.

- Focus on staff development to support and grow staff strengths.
- Target ways to improve patient safety data collection regarding falls and infections.
- Further integrate lean principles into daily practice.

1. **High Quality Outcomes**
    - Comply with regulatory requirements regarding quality reporting.
        - Reporting of Medicare HIS data
    - Improve CAHPS survey scores that fell below the national average scores in FY16 under the following domains.
        - Hospice Team Communications
        - Treating Family Member with Respect
        - Getting Help with Symptoms
    - Increase staff knowledge and compliance with CHAP deemed status accreditation standards, including preparedness for a deemed status survey, scheduled to occur in FY2017.
        - Prepare CHAP Leaders group
        - Perform mock survey
        - Educate staff
        - Renew deemed status accreditation
    - Create a Protocol Committee to develop standard work around clinical practice.
        - Review and edit existing protocols
        - Develop protocols as needed

2. **Support and Grow Staff Strengths**
    - Enhance staff skills by implementing supervisory visits and on-site competency assessment and coaching for 100% of staff who provide direct patient care, to include nurses, hospice aides, social workers, chaplains, bereavement counselors and volunteers.
        - Review and enrich supervisory visit content to determine competence and identify needs for education.
        - Design daily metrics to measure outcomes for supervisory visits and educational needs.
    - Redesign Utilization Review Committee and associated audits to focus on quality of documentation in addition to appropriate service utilization.
        - Identify criteria for assigning random UR audits and implement new system.
        - Use the UR Committee to approve all live discharges due to the patient no longer meeting eligibility guidelines for hospice care.

3. **Improve Patient Safety Data Collection**
    - Enhance the Hospice's Infection Prevention plan to include a focused list of surveillance data to track in the fiscal year and increased participation in activities of the Carroll Hospital Infectious Disease Committee.
    - Identifying patient safety risks and increase same-day reporting of patient falls and infection.
    - Measure, analyze and track adverse patient events.

4. **Integrate Lean Principles into Daily Practice**
    - Assess current data collection tools and processes for redundancy and define a succinct set of measures for focus in the fiscal year.
    - Continue to utilize Lean management principles to target performance improvement

objectives.

- Continue use of daily huddle with new emphasis on identifying patient safety risks.
- Implement use of daily metrics for measurement of performance improvement as needed.

Goals

1. **High Quality Outcomes**
   - Compliance with Regulatory Requirements
     - 90% reporting of Medicare HIS data
   - Improvement of CAHPS Survey Scores
     - Percent of top box scores for Survey Question 14 (Hospice team listened carefully about problems with care): 81.8% (FY16 score: 79.3%)
     - Percent of top box scores for Survey Question 11 (Patient was treated with dignity and respect): 94.9% (FY16 score: 91.8%)
     - Percent of top box scores for Survey Question 25 (Patient received help for constipation): 71.7% (FY16 score: 71.6%)
   - Compliance with CHAP Accreditation Standards
     - 0 CHAP survey findings related to patient safety

2. **Support and Grow Staff Strengths**

   - Supervisory visits and on-site competency assessment for staff who provide direct patient care
     - 100% supervisory visits for direct-care staff and volunteers
   - Redesign Utilization Review Committee and associated audits
     - 120 records audited
     - 100% participation by nursing staff

3. **Improve Patient Safety Data Collection**

   - Focused surveillance data collected daily
     - Increase reporting of UTIs to include 60% of identified infections
     - Increase reporting of C. diff infections to include 60% of identified infections
   - Increase same-day reporting of falls data
     - Increase reporting of falls to include 80% of identified falls
   - Measure, analyze and track adverse patient events.
     - Implement a plan of correction where applicable
     - Conduct a Root Cause Analysis for each sentinel event

4. **Integrate Lean Principles into Daily Practice**

   - Lean events for FY2017:
     - Transfers In and Out of the Dove House Inpatient Unit
     - Bereavement
     - Interdisciplinary Group (IDG)

Performance Measures for the FY17 Quality Improvement and Patient Safety Plan

Executive Summary

1. High Quality Outcomes

Name	**HIS Data Submission**
Definition	Submission of HIS data for each admission and each discharge must be complete within 30 days of the date of admission or discharge. Beginning January 1, 2016, for the 2018 reporting year, hospices must submit at a minimum 70% of required HIS records. For the 2019 reporting year, 80%; for the 2020 reporting year, 90%.
Data Collection	**How:** CMS produces submission reports to track successful data submission. **Method:** The Executive Assistant will pull the submission reports on a monthly basis and provide them to the Manager, PI for report out. **Frequency:** Quarterly reported through Hospice Corporate Compliance **Who:** Laura Welty, Manager of Performance Improvement
Assessment Frequency	The percentage of total HIS data submission will be reviewed by the QAPI Committee on a monthly basis. **GOAL: 90% of required HIS records will be submitted for FY2017.**

Name	**CAHPS Communications**
Definition	Question 14 on the CAHPS Hospice Survey asks the respondent whether the hospice team listened carefully about problems with care. The top box score will reflect the amount of respondents who chose "Always" on their survey responses.
Data Collection	**How:** DEYTA administers and produces reports for the CAHPS Hospice survey. **Method:** CAHPS survey results will be downloaded and distributed to the QAPI Committee at least monthly for review. Responses to question 14 will be isolated on a QI dashboard. **Frequency:** Monthly for the duration of the fiscal year. **Who:** Gail Forsyth, Accreditation and Quality Specialist
Assessment Frequency	All CAHPS hospice survey results will be reviewed by the QAPI Committee on a monthly basis. **GOAL: The top box score for CAHPS Q14 will increase to 81.8%, the national average top box score in FY16.**

Name	**CAHPS Respect**
Definition	Question 11 on the CAHPS Hospice Survey asks the respondent whether the patient was treated with dignity and respect. The top box score will reflect the amount of respondents who chose "Always" on their survey responses.
Data Collection	**How:** DEYTA administers and produces reports for the CAHPS Hospice survey. **Method:** CAHPS survey results will be downloaded and distributed to the QAPI Committee at least monthly for review. Responses to question 36 will be isolated on a QI dashboard. **Frequency:** Monthly for the duration of the fiscal year. **Who:** Gail Forsyth, Accreditation and Quality Specialist
Assessment Frequency	All CAHPS hospice survey results will be reviewed by the QAPI Committee on a monthly basis. **GOAL: The top box score for CAHPS Q11 will increase to 94.9%, the national average top box score in FY16.**

Name	**CAHPS Symptoms**
Definition	Question 25 on the CAHPS Hospice Survey asks the respondent whether the patient received help for constipation. The top box score will reflect the amount of respondents who chose "Always" on their survey responses.
Data Collection	**How:** DEYTA administers and produces reports for the CAHPS Hospice survey. **Method:** CAHPS survey results will be downloaded and distributed to the QAPI Committee at least monthly for review. Responses to question 36 will be isolated on a QI dashboard. **Frequency:** Monthly for the duration of the fiscal year. **Who:** Gail Forsyth, Accreditation and Quality Specialist
Assessment Frequency	All CAHPS hospice survey results will be reviewed by the QAPI Committee on a monthly basis. **GOAL: The top box score for CAHPS Q25 will increase to 71.7%, the national average top box score in FY16.**

2. Support and Grow Staff Strengths

Name	**Supervisory Visits**
Definition	All Carroll Hospice associates and volunteers who provide direct patient care will receive at least one supervisory visit during the fiscal year. This will include all nursing staff, hospice aides, social workers, chaplains and volunteers who provide direct patient care. During these visits, clinical competencies specific to each discipline will be assessed and documented.
Data Collection	**How:** Clinical Managers and other supervisory staff will perform supervisory visits and document the findings of those visits as annual competence assessments. **Method:** Each team manager will be responsible for completing at least one supervisory visit for each team member. The Volunteer Coordinator will perform the visits for volunteers. Other nurse managers will provide support to complete the visits as needed. **Frequency:** Supervisory visits will be completed as needed on a monthly basis. Completed supervisory visits will be reported to Gail Forsyth at the close of each month. **Who:** Gail Forsyth, Accreditation and Quality Specialist
Assessment Frequency	The number of completed supervisory visits will be assessed on a monthly basis. **GOAL: Supervisory visits complete for 100% of direct care staff and volunteers.**

Name	**UR Audits**
Definition	The UR Committee will be responsible for auditing the charts and approving the discharge of any patient who is discharged alive, prior to the discharge. Additionally, clinical records will randomly be assigned for review on a monthly basis.
Data Collection	**How:** The UR Committee will conduct UR audits. **Method:** The standing members of the UR Committee will review all clinical records for patients who are referred for live discharge. UR audits will be assigned randomly to equal 120 audits annually. **Frequency:** UR audits for discharge referrals will be completed as needed; random UR audits will be assigned and completed on a monthly basis. **Who:** Gail Forsyth, Accreditation and Quality Specialist

Assessment Frequency	The number of completed UR audits will be reviewed on a monthly basis. Attendance at the UR Committee will be mandatory and tracked on a regular basis. **GOAL: Complete 120 UR audits.** **GOAL: 100% of nursing staff will participate in the UR Committee.**

3. **Improve Patient Safety Data Collection**

Name	**Surveillance Data**
Definition	Submission of surveillance data will be required for each confirmed UTI and C. diff infection. Surveillance data reported will be in addition to documentation of the infection in the electronic medical record (EMR).
Data Collection	**How:** Data will be submitted through triage and Infection Report forms. **Method:** Staff providing direct patient care will be educated to report confirmed infections in real time. Each reported case will be compared with the EMR to confirm that at least 60% of infections documented in the EMR are also reported as surveillance data. **Frequency:** Data will be collected on a daily basis and analyzed monthly at the QAPI meetings. **Who:** Gail Forsyth, Accreditation and Quality Specialist
Assessment Frequency	The percentage of total surveillance data submitted will be reviewed by the QAPI Committee on a monthly basis. **GOAL: Increase reporting of UTIs to include 60% of identified infections.** **GOAL: Increase reporting of C. diff infections to include 60% of identified infections.**

Name	**Falls Data**
Definition	Submission of falls data will be required for each patient fall, regardless of whether the patient was injured. Falls will be reported for data collection in addition to documentation of the fall in the electronic medical record (EMR).

Data Collection	**How:** Data will be submitted through triage and Patient Safety Report forms. **Method:** Staff providing direct patient care will be educated to report falls in real time. Each reported fall will be compared with the EMR to confirm that at least 90% of falls documented in the EMR are also reported as patient safety data. **Frequency:** Data will be collected on a daily basis and analyzed monthly at the QAPI meetings. **Who:** Gail Forsyth, Accreditation and Quality Specialist
Assessment Frequency	The falls data submitted will be reviewed by the QAPI Committee on a monthly basis. **GOAL: Increase reporting of falls to include 80% of identified falls.**

Exhibit 20

Need

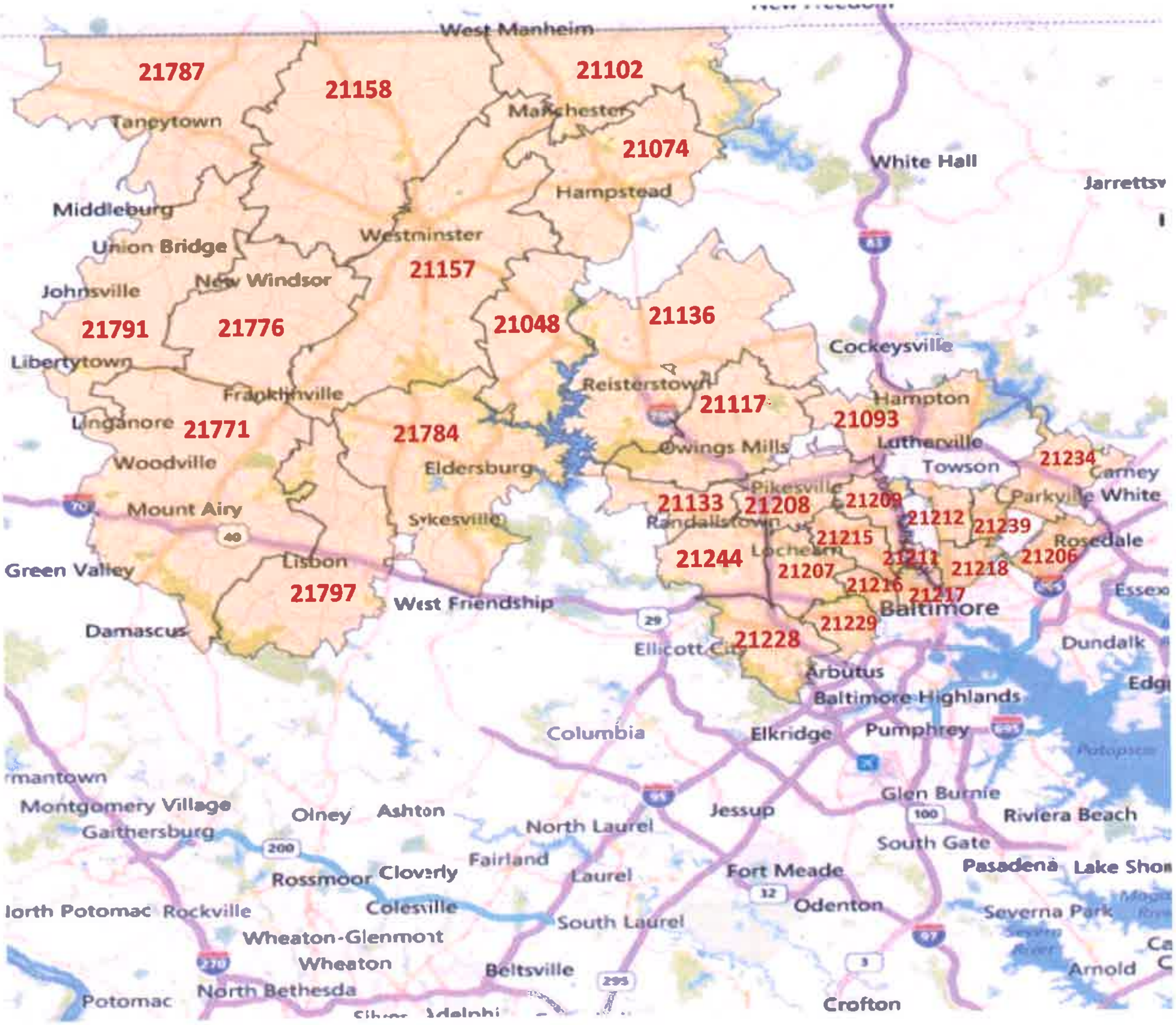
(Question 15 D)

Map: LifeBridge Health Services Area Zip Code Definition

Map: LifeBridge Health Services Area Zip Code Definition

Exhibit 20

LifeBridge Health service area Zip code Definitions



Zip Code	PSA/SSA
21048	PSA
21074	PSA
21102	PSA
21117	PSA
21133	PSA
21136	PSA
21157	PSA
21158	PSA
21207	PSA
21208	PSA
21209	PSA
21215	PSA
21216	PSA
21244	PSA
21784	PSA
21787	PSA
21093	SSA
21206	SSA
21211	SSA
21212	SSA
21217	SSA
21218	SSA
21228	SSA
21229	SSA
21234	SSA
21239	SSA
21771	SSA
21776	SSA
21791	SSA
21797	SSA