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# Palliative Care and Quality of Life Study Committee Report

## *Executive Summary*

In 2018, joint resolution H. 4935 created the South Carolina Palliative Care and Quality of Life Study Committee. The study committee was tasked with creating a report on the state of palliative care in South Carolina with findings and recommendations to submit to the Governor and General Assembly by the end of 2019.

At its core, palliative care is simply about helping those with a serious illness to live as well as possible for as long as possible and to be honored as humans in that process. Research has estimated that fewer than 15% of people living with serious illness who could benefit from palliative care actually receive it.<sup>1</sup> Once informed, 92% of consumers in a public opinion study felt positively about palliative care and reported a high likelihood of wanting to access those services if they or a loved one had a serious illness.<sup>2</sup>

The study committee has identified the following key opportunities for enhancing palliative care access in South Carolina:

### **Education and Awareness**

- Establish a permanent State Advisory Council on Palliative Care and Quality of Life to continue the task of consulting and advising the Governor and General Assembly on matters related to the establishment, maintenance, operation, and outcome evaluation of palliative care initiatives in the state.
- Ensure that accurate information and education on palliative care is available to the public at the community, consumer and family level, including maintenance and funding of a statewide Palliative Care website and awareness campaign by the SC Department of Health and Environmental Control (DHEC).
- Develop an online resource guide on Palliative Care education for the state.

### **Technology**

- Establish a statewide registry to ensure timely access to POST (Physician Orders for Scope of Treatment) forms and advanced care planning documents.
- Offer online continuing palliative care education curriculum for health care professionals.
- Promote utilization of telehealth to increase access of palliative care statewide, including prison system.
- Maintain a website with publicly available information, including support for family/caregivers.

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<sup>1</sup> Lynch T, Connor S, Clark D. (2013). Mapping levels of palliative care development: a global update. *Journal of Pain and Symptom Management*, 45(6):1094-106.

<sup>2</sup> Center to Advance Palliative Care. (2011). Public Opinion Research on Palliative Care.

[https://media.capc.org/filer\\_public/18/ab/18ab708c-f835-4380-921d-fbf729702e36/2011-public-opinion-researchon-palliative-care.pdf](https://media.capc.org/filer_public/18/ab/18ab708c-f835-4380-921d-fbf729702e36/2011-public-opinion-researchon-palliative-care.pdf)

## **Workforce**

- Recommend state health professional licensure and continuing education requirements include a minimum number of hours of palliative care instruction in both communication skills and symptom management skills.
- Provide funding for education and training to the palliative care workforce in the state.
- Establish state medical education funding and encourage participation in palliative care fellowships.

## **Policy/Regulation**

- Consolidate current statutory advanced care documents to eliminate duplication and provide clarity for consumer, health care providers, and health systems.
- Ensure that guardians of minors with a serious illness, in consultation with the minor's health care professionals, are able to enter into a legally binding POST (Physician Orders for Scope of Treatment) or DNR (Do Not Resuscitate) directive.
- Remove impediments to establishing additional hospice houses in the state.
- Update hospice license regulations to allow hospices to provide non-hospice palliative care.
- Consult with CMS on ability to offer personal care services through Medicaid community-based programs while simultaneously receiving the Medicare hospice benefit.
- Ensure that any policies designed to address the opioid epidemic do not restrict necessary access to these medications for people with a serious illness and those receiving palliative care.

## **Payment Strategies**

- Ensure appropriate reimbursement across payers to medical professionals to encourage advanced care planning discussions during office visits, which would ensure care received by an individual is in line with their values and wishes.
- Explore alternative payment models to enhance delivery of home-based palliative care, especially for children.
- Create a standard set of services beneficial to people in need of palliative care, such as advanced care planning, interdisciplinary team consults, care coordination, and respite for family caregivers.
- Remove payment restrictions for telemedicine to geographic areas with a shortage of palliative care providers.

## **Quality**

- Require hospital- and community-based programs to complete annual Palliative Care Registry Surveys and Community Mapping Project through the Center to Advance Palliative Care (CAPC).
- Develop standards for palliative care programs, including interdisciplinary team focus and resources available to patients, through hospital and nursing home associations.
- Develop licensure requirements that hospitals and skilled nursing facilities to provide access to specialty palliative care teams, as well as staff training on palliative care, communication, and symptom management.
- Identify Centers of Excellence of palliative care practice in South Carolina to support workforce development.

## ***Introduction: What is Palliative Care?***

Palliative care is specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a specially-trained team of doctors, nurses and other specialists who work together with a patient's other doctors to provide an extra layer of support. Palliative care is based on the needs of the patient, not on the patient's prognosis. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with disease modifying treatment. Palliative care is not the same as hospice; hospice is a Medicare benefit provided specifically at the end of life, while palliative care is comprehensive care for a patient with a chronic illness throughout the lifetime.

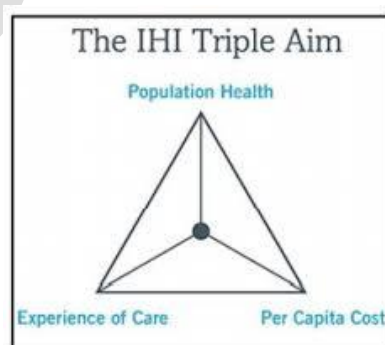
Palliative care can be delivered in many settings: home (the patient's or loved one's), nursing facility, assisted living facility, hospital, clinic, correctional setting, or homeless shelter— wherever the person is located.

## ***Why is Palliative Care Important?***

Palliative care is interdisciplinary expert care focused on patient-centered outcomes such as quality of life, symptom burden, emotional well-being, and caregiver need. Its emphasis on communication and continuity of care fits the episodic and long-term nature of serious, multifaceted illness.

Additionally, palliative care aligns with the Institute for Healthcare Improvement's (IHI) Triple Aim framework for optimizing health system performance. Palliative care improves patient experience of care while managing a high-risk health population at reduced per capita cost to the healthcare system.

Because it focuses on the greatest need in a high-cost patient segment, palliative care is particularly relevant as an essential strategy for high-quality population health management.



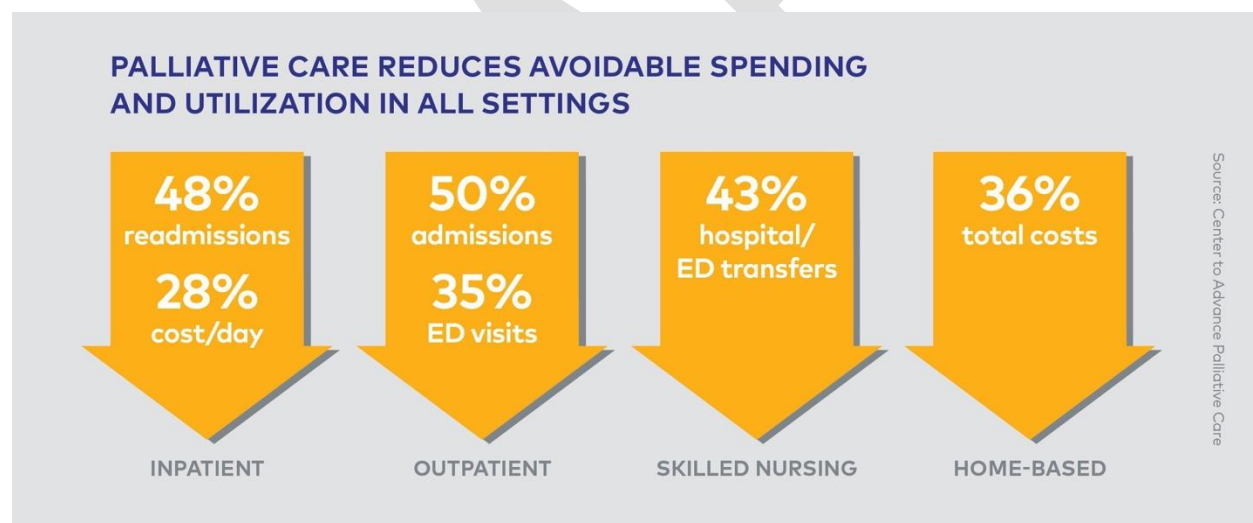
Source: Institute for Healthcare Improvement

### Palliative care teams working in hospitals:

- Improve patient and family satisfaction with care<sup>3</sup>
- Reduce 30-day readmission rates<sup>4</sup>
- Reduce ICU utilization<sup>5</sup>
- Can save 9-25% of costs for each inpatient stay<sup>6</sup> through a mixture of shorter length of stay and reduced cost per day if offered early

### Palliative care teams working in home-based programs:

- Have been shown to save as much as \$12,000 in health care costs per person enrolled<sup>7,8</sup>
- Reduce emergency department visits, hospital admissions and readmissions, and hospital length of stay<sup>9</sup>



Source: Center to Advance Palliative Care

In one study<sup>10</sup>, adults with lung cancer who received palliative care services in addition to chemotherapy experienced improved quality of life and mood. They also received less aggressive

<sup>3</sup> Casarett DS, Shreve C, Luhrs K, et al. (2010). Measuring Families' Perceptions of Care Across a Health Care System: Preliminary Experience with the Family Assessment of Treatment at End-of-life Short Form (FATE-S). *J Pain Symptom Management*, 40:801-809.

<sup>4</sup> Cassel JB, Garrido M, et al. (2018). Impact of Specialist Palliative Care on Re-Admissions: A "Competing Risks" Analysis to Take Mortality into Account. *J Pain Symptom Management*, 2018; 55(2):581.

<sup>5</sup> Khandelwal N, Kross EK, Engelberg RA, Coe NB, Long AC, Curtis JR. (2015). Estimating the Effect of Palliative Care Interventions and Advance Care Planning on ICU Utilization: A Systematic Review. *Crit Care Med*, 43(5):1002-11.

<sup>6</sup> May P, Normand C, Cassel JB, et al. (2018). Economics of Palliative Care for Hospitalized Adults with Serious Illness: A Meta-analysis. *JAMA Intern Med*, 178(6):820-829

<sup>7</sup> Lustbader D, Mudra M, Romano C, et al. (2016). The Impact of a Home-based Palliative Care Program in an Accountable Care Organization. *J Palliat Med*, 20(1):23-28.

<sup>8</sup> Krakauer R, Spettell C, Reisman L, et al. (2009). Opportunities to Improve the Quality of Care for Advanced Illness. *Health Aff*, 28(5).

<sup>9</sup> Scibetta C, Kerr K, Mcguire J, Rabow M. (2016). The Costs of Waiting: Implications of the Timing of Palliative Care Consultation Among a Cohort of Decedents at a Comprehensive Cancer Center. *J Palliat Med*, 19(1):69-75.

<sup>10</sup> Temel J, et al. (2010). Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. *N Engl J Med*, 363:733-742.

care and lived longer than those patients who did not receive palliative care services in addition to chemotherapy.

Palliative care is appropriate at any age, and there is growing evidence of the benefits of pediatric palliative services in the healthcare system. One study showed that enrollment of pediatric patients in a home-based palliative care program was associated with an average decrease in total length of stay by 38 days and a decrease in total hospital charges of nearly \$275,000 over at least six months.<sup>11</sup> In California, a community-based palliative care program resulted in an average savings of \$1,677 per child per month in health care costs.<sup>12</sup> One retrospective study showed that children with complex, chronic conditions account for 19.2% of admissions yet 48.9% of hospital days and 53.2% of hospital charges. This patient population is expensive, at high risk of suboptimal care, and often draws reimbursement at rates insufficient to cover inpatient care costs.<sup>13</sup>

## ***Current State of Palliative Care in South Carolina***

**It is difficult to quantify the ongoing burden of serious illness in South Carolina, but it is estimated that of South Carolinians who died in 2018, 53.8% would have been eligible for palliative care.** These 27,245 deaths resulted from major chronic conditions: cancer, traumatic brain injury, congestive heart failure, kidney disease, chronic obstructive pulmonary disease, Alzheimer's Parkinson's and motor neuron diseases.<sup>14</sup>

**The need for palliative care also affects families and communities, not just the individual. The total impact is unknown, but it is estimated that 313,000 South Carolinians served as caregivers in 2018 for individuals with Alzheimer's /dementia alone.** These caregivers provided about 357 million hours of unpaid care, valued at more than \$4.5 billion.<sup>15</sup>

**More palliative care programs are needed to serve this demand.** Appendix A shows the number of palliative care facilities and programs available in each county.

### **Hospital-Based Programs**

An acute care hospital is the most common place for palliative care delivery. Hospitals are major entry points to the healthcare system and are the place where patients receive active but short-term

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<sup>11</sup> Postier A, et al. (2013). Exposure to Home-Based Pediatric Palliative and Hospice Care and Its Impact on Hospital and Emergency Care Charges at a Single Institution. *J Palliat Med*.

<sup>12</sup> Gans D, et al. (2012). Better outcomes, lower costs: palliative care program reduces stress, costs of care for children with life-threatening conditions. Policy Brief UCLA Cent Health Policy Res, PB2012-3:1-8.

<sup>13</sup> Berry JG, et al. (2013). Inpatient growth and resource use in 28 children's hospitals: a longitudinal, multi-institutional study. *JAMA Pediatr*, 167(2):170-7.

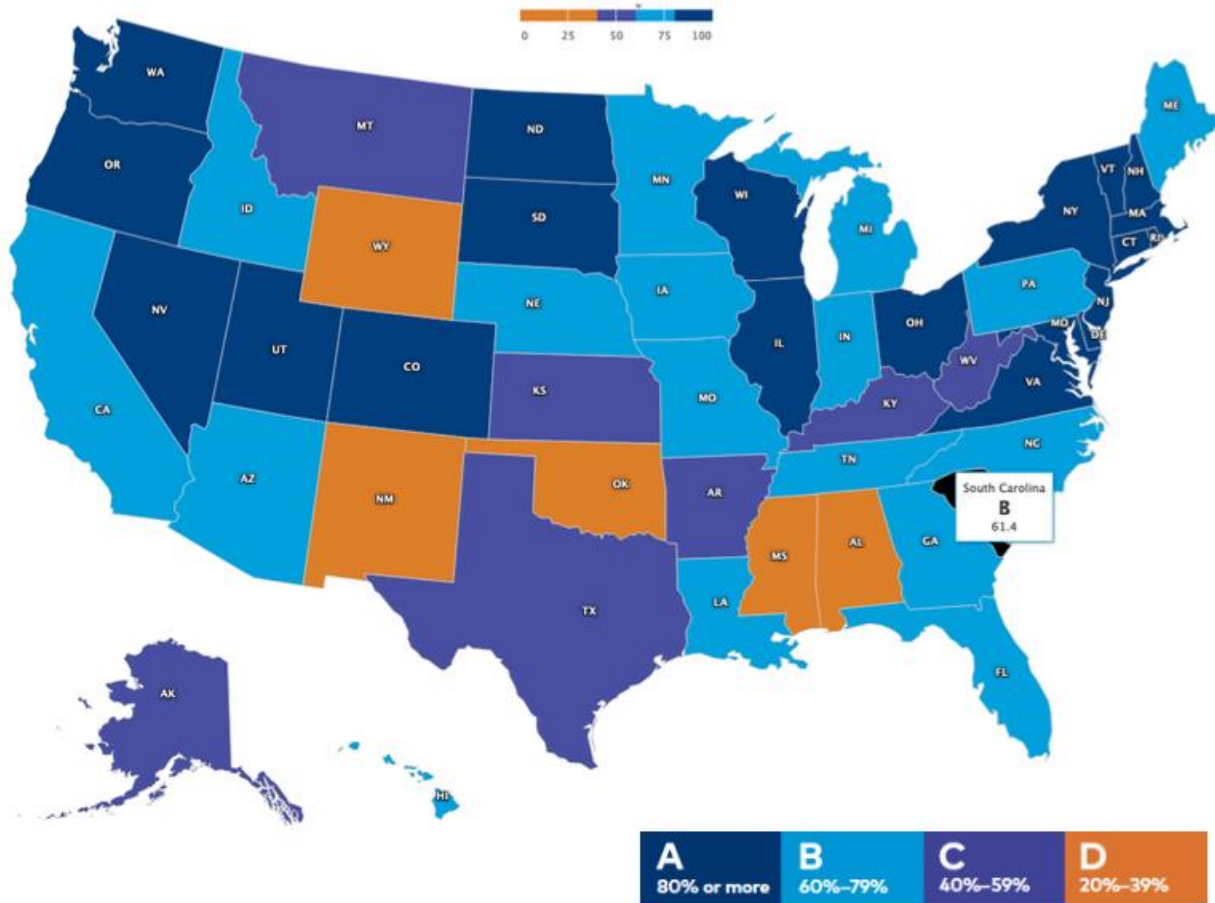
<sup>14</sup> 53% estimated based on number of deaths from major chronic diseases out of total (50,633). Source: DHEC Public Health Statistics, 2018.

<sup>15</sup> Alzheimer's Association. (2019).



treatment for a severe injury or episode of illness, an urgent medical condition or during recovery from surgery. There are 105 hospitals in South Carolina.

In the Center to Advance Palliative Care (CAPC)'s 2019 report card on hospital access to palliative care, South Carolina received a B grade, the state's highest score to date. In 2008, the state received a D grade, and in 2011 and 2015, South Carolina received a C grade. While South Carolina has seen an improvement, more progress can still be made, particularly in areas outside the state's major cities.



Source: Center to Advance Palliative Care

CAPC determines its grades primarily based on the presence of a palliative care program as reported by hospitals in an annual American Hospital Association survey or an internal CAPC survey. In 2018, 61.4% of participating South Carolina hospitals with 50 or more beds reported having a palliative care program. Nonprofit hospitals were significantly more likely to have a program than for-profit hospitals (77% vs 29%). CAPC grades evaluate the presence of programs but does not assess level of services provided. The state should continue to make progress with delivery of high-quality palliative care programs in hospitals.



State	Letter Grade	Number Grade	Total Programs/ Hospitals	By Hospital Type			Sole Community Provider	>300 beds	<50 beds*
				Nonprofit	For-Profit	Public			
South Carolina	B	61.4	(27/44)	77.2 (17/22)	28.5 (4/14)	75.0 (6/8)	40.0 (2/5)	92.3 (12/13)	46.2 (6/13)

### Community-Based Programs

South Carolina also has ambulatory (clinic) and community (home) based palliative care services. Community-based or ambulatory palliative care includes not only the patient’s private residence but also assisted living, independent living, or nursing home facilities. By meeting the patient at home or in their environment, practitioners can not only address the health needs of the patient but also the social determinant needs such as food insecurity, caregiver fatigue, and transportation needs that all contribute higher cost of care. There are a number of palliative care programs throughout the state, some hospital-based, that deliver services in the home. Those needing palliative care can access directories through [GetPalliativeCare.org](http://GetPalliativeCare.org) and the [American Academy of Home Care Medicine](http://AmericanAcademyofHomeCareMedicine.org) that list programs delivering services in various settings.

### Facility-Based Programs

Facility-based palliative care is delivered through palliative care consultations or internal palliative care teams. There is currently no formal regulation for palliative care services in nursing home or community residence facilities.

Board	Number *
Nursing Homes	195
Community Residence Facilities (Assisted Living Facilities, Care Homes)	502
Hospice Houses	13

\*Current as of Nov. 2019.

### Hospices

Outpatient hospice services, provided in the community setting (patient residence, assisted living programs or skilled nursing facilities) are provided on an intermittent basis by skilled members of the interdisciplinary team. The hospice interdisciplinary team is led by the hospice medical director, who in addition to the patient’s primary physician, is charged with ensuring that the patient is eligible for hospice services. Hospice services include, but are not limited to, nursing, social work, spiritual care, volunteer support and nursing assistant care. All programs provide 24-hour on call availability with specific emphasis on nursing support as needed after hours. The focus of the interdisciplinary hospice team is to provide relief of pain and symptom management and to provide psychosocial and spiritual support for the patient and caregivers. Due to the nature of the services provided, families often require additional in-home support for custodial caregiving needs not provided by the hospice program.

Hospice programs are reimbursed primarily through Medicare, Medicaid, and other commercial payers. The payment structure for these services are based on the level of care provided to the patient, such as routine home care, inpatient care, inpatient respite or continuous home care

(utilized for acute symptom management in the home setting). Approximately 51% of Medicare patients in SC received hospice services.<sup>16</sup>

Hospice care is provided for patients who are in the last stages of a life limiting illness, usually with a six-month prognosis certified by their attending physician and the hospice medical director. However, hospice services are often not referred in a timely manner and the Medicare hospice benefit is underutilized; approximately 28% are on service for fewer than seven days. More education for consumers and clinicians on the benefits of receiving hospice services could improve timeliness of referrals.

There are currently 84 licensed outpatient hospices, which provide home-based hospice services in all 46 counties. In addition, 13 of the 84 licensed programs also operate free-standing inpatient hospice facilities, which provide acute medical services and/or inpatient respite as mandated by the Medicare Conditions of Participation when indicated by the patient's medical condition and approved by the hospice physician and interdisciplinary team.

The DHEC Division of Health Licensing licenses all hospice programs in the state. Hospice programs that receive federal funding from the Centers for Medicare and Medicaid must pass an initial certification survey conducted by the SC DHEC Bureau of Certification. In addition, all hospice programs are mandated to receive an annual inspection and complete Medicare certification surveys every three years. However, there are no Certificate of Need (CON) requirements to open an outpatient hospice facility, which often cover multiple counties. DHEC maintains a list of current Outpatient and Inpatient Hospice Programs.

### **Pediatric Palliative Care**

The three largest children's health systems in the state—[MUSC Children's Health System](#), [PRISMA Health Children's Hospital-Midlands](#), and [PRISMA Health Children's Hospital-Upstate](#)—all have palliative care programs for children. These services are provided in the hospital and in clinics, including fetal medicine and perinatal palliative care services.

South Carolina is unique in the US in that there is one pediatric-specific hospice program that is able to serve the entire state, allowing for concentration of pediatric-specific expertise. [Hands of Hope](#) provides home-based hospice and palliative care services to children living with serious illness. Other hospices in the state consider accepting children; however, Hands of Hope is the only hospice staffed with full-time pediatricians, pediatric certified nurses, social workers, and child life specialists.

Unfortunately, there are no fellowships spots for physicians focused on pediatric hospice and palliative medicine.

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<sup>16</sup> National Hospice and Palliative Care Organization (NHPCO). (2018). NHPCO Facts and Figures. <https://www.nhpc.org/nhpc-releases-updated-edition-of-hospice-facts-and-figures-report/>

**Conclusion: South Carolina must continue to make progress in offering more and higher-quality palliative care services across the state in various settings.**

## *Workforce Assessment: Certified Palliative Care and Hospice Specialists in South Carolina*

### **Physicians**

Palliative medicine has only been a board-certified medical specialty since 2012. Nationally, there are 6,600 board-certified physicians, with a projected shortage of 18,000 physicians based on estimated need.<sup>17</sup> According to the American Board of Medical Specialties, as of 2018 there are only 104 board-certified physicians in South Carolina. The actual number of physicians practicing hospice and palliative medicine is likely significantly lower than 104, because this figure includes physicians not actively practicing in the specialty as well as physicians who have retired. There are currently six physician fellowships specifically for hospice and palliative medicine, none of which focuses on pediatrics. Of those spots, only two of the available six were filled for the 2020-2021 training year. More needs to be done to incentivize filling these slots to meet future palliative care needs.

Board	Subspecialty	Number
Anesthesiology	Palliative Medicine	1
Emergency Medicine	Palliative Medicine	0
Family Medicine	Palliative Medicine	38
Internal Medicine	Palliative Medicine	60
Obstetrics and Gynecology	Palliative Medicine	1
Pediatrics	Palliative Medicine	2
Physical Medicine and Rehabilitation	Palliative Medicine	0
Preventive Medicine	Palliative Medicine	0
Psychiatry and Neurology	Palliative Medicine	3
Radiology	Palliative Medicine	0
Surgery	Palliative Medicine	0
	<b>TOTAL</b>	<b>104</b>

Additionally, there are 16 physicians who are hospice medical directors as certified by the [Hospice Medical Director Certification Board](#).

### **Nurses**

As of May 2019, there are 219 nurses with palliative care certification, 26 are advanced practice nurses, 6 are licensed nurses, 177 are registered nurses and 10 are pediatric registered nurses. There are 107 certified nursing assistants.

<sup>17</sup> Kamal, AH, Bull, JB, Swetz, KM, Wolf, SP, Shanafelt, TD, Myers, ER. (2017). Future of the Palliative Care Workforce: Preview to an Impending Crisis. *Am Journal of Medicine*. 130(2).

Palliative Care Certified Nurses	
ACHPN—Advanced Practice Nurses	26
CHPLN—Licensed Nurses	6
CHPN—Registered Nurses	177
CHPNA—Nursing Assistants	107
CHPPN—Pediatric Registered Nurses	10
CPLC—Certified in Perinatal Loss	3
<b>TOTAL</b>	<b>219</b>

### Social Workers

The [Social Work Hospice and Palliative Network](#) first offered specialty certification in 2018. While social work is at the core of comprehensive palliative care delivery, there are currently only six social workers in South Carolina who have obtained this certification.

Social workers provide services that are core to a comprehensive palliative care service. One major hospital-based program in the state has been unable to fill an available social worker position.

**Conclusion: South Carolina has a dire shortfall of trained professionals throughout the state to serve the growing number of citizens in need of palliative care.**

## *Creating Opportunities for Palliative Care*

Through review of the state of palliative care in South Carolina, research and reports from national stakeholders, and public presentations from state partners, the study committee identified the following recommendations to improve awareness of, access to, and quality of palliative care services for South Carolinians. This section provides background and rationales to support these recommendations.

### Education and Awareness

- Establish a permanent State Advisory Council on Palliative Care to continue the task of consulting and advising the Governor and General Assembly on matters related to the establishment, maintenance, operation, and outcome evaluation of palliative care initiatives in the state.

**Rationale:** Delivery of healthcare and best practices in palliative care are rapidly evolving at the state and national level. A continued advisory committee would provide relevant, comprehensive, and accurate information on the development of policy and practice around palliative care in South Carolina. The committee would continue to review services and make recommendations to improve accessibility to high quality palliative care services for patients and families living with serious illness in South Carolina, to include any age or any stage of serious illness.

- Ensure that accurate information and education on palliative care is available to the public at the community, consumer and family level, including maintenance and funding of a statewide Palliative Care website and awareness campaign by DHEC.

**Rationale:** Although most large hospitals have palliative care programs and palliative care as a subspecialty continues to grow in recognition, a major barrier to access to palliative care is a misunderstanding of the goals of palliative care and what it represents. A recent study<sup>18</sup> found that over half of participants expressed at least one misperception about palliative care, most commonly that it was associated with end-of-life care or only for the elderly. A large nationwide survey of adults also found that over 70% of participants self-reported low to no knowledge of palliative care.<sup>19</sup> Enhancing the general public's knowledge of the role of palliative care can encourage uptake of high-quality services to complement efforts to increase access. As the state's public health agency, DHEC is a good fit for offering health promotion and education that is generalized to all ages and socioeconomic demographics.

- Develop an online resource guide for Palliative Care education for the state.

**Rationale:** Education of what palliative care, hospice care, and advanced care planning is and who is eligible would increase the utilization of such services and has been proven to increase quality of life and decrease cost of end-of-life care. Palliative care promotes medical decisions and individualized goals of care that are based on patient values. Increasing awareness of current services available is a priority. Palliative care education should normalize consumer, family, and provider communication about medical care decisions in consumers with serious medical illness and/or at end of life. A resource guide will help the public and practitioners connect to palliative care resources available online and throughout the state.

## Technology

- Establish a statewide registry to ensure timely access to POST (Physician Orders for Scope of Treatment) forms and advanced care planning documents.

**Rationale:** Advance Care Planning (ACP) involves specific activities designed to communicate healthcare directives and medical orders. The South Carolina Care for the Seriously Ill (CSI) Coalition continues to develop ACP education and communication tools available to all organizations in the state. Access to documents such as the HCPOA, POST, and Serious Illness Conversation (SIC) Guide, remains a challenge for caregivers and clinicians. In order to address the access issue, CSI has identified a technology solution that allows important POST and ACP information and documents to be viewed and retrieved at the point of patient care. The SC ACP My Life My Choices eRepository is an online searchable database that is able to accept uploaded documents, create new documents, and guide conversations that direct ACP decisions. The eRepository can then be accessed by registered

<sup>18</sup> Shalev A, Phongtankuel V, Kozlov E, Shen MJ, Adelman RD & Reid MC. (2017). Awareness and Misperceptions of Hospice and Palliative Care: A Population-Based Survey Study. *American Journal of Hospice and Palliative Medicine*; 35 (3):431-439. doi.org/10.1177/1049909117715215

<sup>19</sup> Center to Advance Palliative Care. (2011). 2011 Public Opinion Research on Palliative Care.

[https://media.capc.org/filer\\_public/18/ab/18ab708c-f835-4380-921d-fbf729702e36/2011-public-opinion-researchon-palliative-care.pdf](https://media.capc.org/filer_public/18/ab/18ab708c-f835-4380-921d-fbf729702e36/2011-public-opinion-researchon-palliative-care.pdf)

organizations for the ACP needs of their patients and clients. This eRepository solution satisfies the requirement under the POST law to provide access to these documents.

- Offer online continuing palliative care education curriculum for health care professionals.

**Rationale:** Online courses can help health care providers overcome challenges in receiving palliative care training by providing high-quality education and at the learner's own location and pace without the need for burdensome travel or lengthy periods of being away from caregiving duties.

- Promote utilization of telehealth to increase access of palliative care statewide, including prison system.

**Rationale:** MUSC has launched a statewide, palliative care telehealth program to offer palliative services to South Carolina's rural population and provide palliative education. The telehealth program addresses statewide provider shortages that impact access to palliative care. The telehealth service is a complement to the care patients receive during an admission, including pain and symptom management, advanced care planning, and supportive care. The program has potential to improve quality and access to care, but faces several challenges, including:

- Medicare reimbursement restrictions by geographic area
- No requirements for private payer parity
- Palliative education deficit
- Rural site infrastructure

MUSC promotes making policy and system changes that enable telehealth access and incentivizing uptake of these services is key to enabling increased palliative care access statewide.

## **Workforce**

- Recommend state health professional licensure and continuing education requirements include a minimum number of hours of palliative care instruction in both communication skills and symptom management skills.

**Rationale:** As awareness grows through educational efforts, South Carolina should also increase access to care through a network of trained professionals by ensuring all healthcare professionals receive training and continuing education to enhance primary palliative care skills. Every healthcare professional should have the skills to communicate effectively, screen for the presence of physical and other forms of suffering, and work to ensure that the medical care received by an individual with serious illness is aligned with that individual's own desires and values. Primary palliative care skills can ensure palliative care needs are met in smaller hospitals and other facilities in which a robust specialty program cannot reasonably be supported.

- Provide funding for education and training to the palliative care workforce in the state.

**Rationale:** Broad primary care education in partnership with the Area Health Education Consortium (AHEC) and provider associations should be prioritized as an efficient strategy to achieve maximum reach for education and training.

- Establish state medical education funding and encourage participation in palliative care fellowships.

**Rationale:** Palliative care delivery in the healthcare system can also be fostered by developing of interdisciplinary specialist palliative care programs, which require healthcare professional to undergo extensive specialty training (physician hospice and palliative medicine fellowships) and certification (nursing and social work) processes. Creating and promoting these specialized programs can be time and resource intensive but is still an important complement to basic generalized continuing education requirements. There are currently six physician fellowships specifically for hospice and palliative medicine, none of which specialize in pediatrics. Of those spots, only two of the available six filled for the 2020-2021 teaching year.

## **Policy/Regulations**

- Consolidate current statutory advanced care documents to eliminate duplication and provide clarity for consumers and health care providers.

**Rationale:** Many of the advanced directives available to consumers have overlapping content. These documents could be streamlined to provide clarity for consumers as well as health care providers. For example, the recent addition of the Physician Orders for Scope of Treatment (POST) may eliminate the need for the EMS Do Not Resuscitate (DNR) form because the POST form includes options for the patient to choose to a DNR option and is available for EMS personnel. In addition, the SC Health Care Power of Attorney (HCPOA) and the Living Will have overlapping sections and can be confusing. The SCHCPOA is comprehensive and is less burdensome to execute than the living will. All of these documents should be reviewed and streamlined to provide ease of use and clarity for consumers as well as health care providers.

- Ensure that guardians of minors with a serious illness, in consultation with the minor's health care professionals, are able to enter into a legally binding POST (Physician Orders for Scope of Treatment) or DNR (Do Not Resuscitate) directive.

**Rationale:** It is crucial that a legal guardian of a child with a serious illness is able to establish clear goals of medical care for their minor child, in consultation with that child's health care team. As currently established in South Carolina, legislation around DNR and POST orders are exclusive of being applied to minors. Currently, legal guardians are able to make decisions around end-of-life wishes for their child when in a hospital setting. It is crucial that families are granted this freedom for their minor child when in the home. Without this statutory protection, children with serious illness are at risk of receiving medical care that is either



ineffective or not deemed appropriate by the legal guardian in consultation with a medical professional.

- Remove impediments to establishing additional hospice houses and the utilization of hospice houses in the state by other hospice providers who do not own an inpatient facility.

**Rationale:** The state's Certificate of Need (CON) requirements and process can be a challenge to establishing new hospice house facilities in the state. In addition, many of the state's hospice providers with an inpatient hospice facility limit access of other provider's hospice patients to their facility. Often, this is done by requiring the hospice patient to change providers. This practice is not mandated by licensing or the Medicare Hospice Conditions of Participation. South Carolina has 13 inpatient hospice houses currently. Georgia does not have CON requirements for hospice outpatient or inpatient facilities.

- Update hospice license regulations to allow hospices to provide non-hospice palliative care.

**Rationale:** Hospice providers are in a unique position due to the interdisciplinary care and medical oversight provided to support seriously ill patients and their families earlier when appropriate and desired by the patient and caregiver. Although hospice provides palliative care during the last six to 12 months of life, current licensing regulations do not provide oversight for hospice providers to work with those not eligible for hospice. Current hospice regulations should be amended to allow hospice providers to provide palliative care services for seriously ill patients who are not eligible for hospice services or do not desire hospice services. This would allow hospice providers to work with commercial payers and others to provide these types of services to their members.

- Consult with CMS on ability to offer personal care services through Medicaid community-based programs while simultaneously receiving the Medicare hospice benefit.

**Rationale:** Medicare covers personal care as a component of hospice services. Community long term care participants can receive personal care services as part of a Medicaid waiver. These participants can enroll in hospice when the time is appropriate, but the responsibility for personal care services transfers to the hospice provider to avoid duplication of services across the two programs. However, the degree of personal care provided through hospice does not match the number offered of hours offered by community-based Medicaid waiver programs, which causes a barrier for participants in choosing to elect the Medicare hospice benefit. The degree of personal care to be delivered through hospice should be defined in consultation with CMS for clarity for both providers and participants in services.

- Ensure that any policies designed to address the opioid epidemic do not restrict necessary access to these medications for people with a serious illness and those receiving palliative care.

**Rationale:** While the misuse of opioids is a serious threat to the health of South Carolinians, opioids remain a highly effective treatment for specific patients and disease conditions. This is especially true for patients receiving palliative care. The development of policies restricting opioid access run the risk of negatively impacting those who would benefit from such medications. It is important to ensure that any policies around opioids are thoughtful in regard to the impact such policies might have on patients receiving palliative care and hospice services.

## **Payment Strategies**

- Ensure appropriate reimbursement across payers to medical professionals to encourage advanced care planning discussions during office visits, which would ensure care received by an individual is in line with their values and wishes.

**Rationale:** Palliative care is often delivered as a part of complex case management, with clinical triggers to identify patients who might benefit from these services. Patients are informed of these services through care management and disease management education. However, many services are underutilized. An important entry point to palliative care services is a conversation with a trusted medical professional. Primary care physicians and other medical professionals can begin the conversation through advanced care planning and referrals to additional resources and should have incentive to do so. Care managers through payers can also deliver provider education to support physicians with effective conversations. The benefit of completing advanced care discussions in the clinic is that it will lead to healthcare utilization that is in line with an individual's values and preferences. Furthermore, this will result in reduced emergency department visits and hospital admissions.

- Explore alternative payment models to enhance delivery of home-based palliative care, especially for children.

**Rationale:** Financial incentives ensure equitable and reliable access to palliative care for all people living with a serious illness. The traditional fee-for-service model of healthcare creates challenges for palliative care services. Value-based payment models offer an opportunity for palliative care programs to secure sustainable payment for their services, which evidence shows improves quality and reduces spending.

There are a number of programs on the federal, state, and private levels that focus on alternative payment models to enhance access to palliative care through improved reimbursement for services. For example, Blue Cross Blue Shield provides several value-based payment programs that are designed to align provider incentives to improve quality and lower costs. For example, in the patient-centered medical homes program, providers are paid to improve care coordination with a heavy emphasis on higher quality and lower cost. The oncology care management program incentivizes care delivery reform by paying for high value services such as advanced care planning, after-hours services, and transitional care. This program also reimburses services performed by qualified, non-physician healthcare professionals, such as patient education, genetic counseling, hospice referral visits, and nutrition therapy.

South Carolina's Healthy Connections Medicaid also provides a continuum of programs across life stages to promote care management and home-based and community services. Participation in community long term care services and waiver programs, which permit additional services to targeted populations to help stay in community settings, has grown to outpace nursing and hospice stays. Additionally, Healthy Connections Prime, a program for Medicaid/Medicare dual enrollees living in the community, uses a capitated payment structure that incentivizes being in a community setting, are eligible to receive a palliative care benefit with a focus on pain management and comfort care. The Program of All-Inclusive Care for the Elderly (PACE) is another program that promotes a patient-centered, lower-cost end of life care model through primary care medical homes that are licensed as adult day health centers.

For the pediatric population, there remains tremendous opportunity to develop innovative alternative payment models to help deliver high quality palliative care services for children in all regions of the state. The number of children eligible to receive palliative care services are relatively small, allowing for a targeted population in which to develop and study such APMs.

Continuing to explore opportunities for alternative payment models focused on patient outcomes that incentivize comprehensive, interdisciplinary palliative care services will help health care systems will promote health and quality of life while still achieving cost savings.

- Create a standard set of services beneficial to people in need of palliative care services, such as advanced care planning, interdisciplinary team consults, care coordination, and respite for family caregivers.

**Rationale:** A major obstacle payers encounter is the lack of common understanding for what is included in the scope of palliative care services. Providers are not educated about and/or providing the same services. This lack of standardization and understanding of palliative care results in a lack of providers willing to have discussions with members and their families. Consumers and providers can gain clarity from understanding common service categories under the palliative care umbrella, including assessment and consultation, care planning, pain management, mental health services, and care coordination. Rather than being prescriptive about coverage, payers can articulate how these palliative care categories are provided through their plans. This standard can be used to determine appropriate reimbursement.

- Remove payment restrictions for telemedicine to geographic areas with a shortage of palliative care providers.

**Rationale:** Medicare currently determines telemedicine coverage and payment methodology through rurality standards. South Carolina's Medicare providers should eliminate the rurality restrictions on payments for telemedicine services.

## **Quality Standards**

- Require hospital- and community-based programs to complete annual Palliative Care Registry Surveys and Community Mapping Project through the Center to Advance Palliative Care (CAPC).

**Rationale:** Residents of South Carolina, including children, deserve access to high-quality palliative care services. The [National Consensus Project Clinical Guidelines for Quality](#)

[Palliative Care](#) are designed to encourage and guide health care organizations and clinicians, including non-palliative care specialists, across the care continuum to integrate palliative care principles and best practices into their routine assessment and care for all seriously ill patients, including children. State associations can draw from these best practices to develop standards for palliative care programs, including interdisciplinary team focus and resources available to patients. The South Carolina Hospital Association can assist with encouraging its members with timely completion of these reports.

- Develop licensure requirements for skilled nursing facilities to provide access to specialty palliative care teams, as well as staff training on palliative care, communication, and symptom management.

**Rationale:** There is little palliative care being offered in skilled nursing facilities in the state. In the absence of palliative care regulations, there is a great need for the development of minimum care delivery standards to guide health care providers and facilities in their delivery of these services. It is recommended for DHEC to review provider licensure regulations to address palliative care; for example, as part of the licensing renewal process to require for every patient to have an advanced care discussion within 30 days of admission, recurring annually, and review by DHEC for 90% compliance for licensure renewal.

- Identify Centers of Excellence of palliative care practice to support workforce development.

**Rationale:** Due to the growth of palliative care and the need for education, facilities with proven track records in the delivery of palliative care can serve as models to mentor and train others in the state who desire to deliver these services. Online palliative care resources should recognize these facilities for high-quality practice.

## **Conclusion**

Application of these recommendations has the potential to enable South Carolina to: achieve improved national palliative care ratings for programs across the state, expand the workforce trained in palliative care practice, and increase utilization of available services and expand access to more citizens, which has the potential to reduce health care costs and, most importantly, promote improved health outcomes and quality of life for South Carolinians of all ages.

DRAFT

*Appendix A. Palliative Care Facilities and Programs Available by County*

COUNTY	Hospice House		Nursing Home		Asst Living Fac		Hospice Companies		Hospitals		Adult Day Care		Home Health		In Home Care
	Facilities	Beds	Facilities	Beds	Facilities	Beds	Facilities	Counties	Facilities	Beds	Facilities	Limit	Companies	Counties	Companies
Abbeville	0	0	1	74	4	74	0	0	1	25	3	121	0	0	0
Aiken	0	0	6	831	17	670	6	71	1	273	3	95	4	13	18
Allendale	0	0	1	44	3	20	0	0	1	25	2	134	0	0	1
Anderson	1	32	7	971	17	758	2	10	4	793	0	0	3	22	22
Bamberg	0	0	1	88	5	57	0	0	0	0	0	0	1	7	1
Barnwell	0	0	3	173	1	8	0	0	0	0	1	24	0	0	1
Beaufort	0	0	8	638	23	1343	5	63	3	344	1	60	9	33	14
Berkeley	1	30	4	415	9	494	1	15	1	50	1	97	0	0	4
Calhoun	0	0	1	120	2	12	0	0	0	0	1	20	0	0	3
Charleston	1	20	12	1363	59	2235	5	95	11	2058	6	278	10	37	49
Cherokee	0	0	2	243	3	180	0	0	1	125	2	45	1	4	3
Chester	0	0	1	80	3	142	0	0	1	82	1	45	1	4	2
Chesterfield	0	0	2	224	5	212	0	0	1	59	1	60	1	3	4
Clarendon	0	0	2	152	3	29	0	0	2	89	1	83	0	0	6
Colleton	0	0	2	352	3	60	0	0	1	135	1	34	1	9	2
Darlington	0	0	4	418	5	193	1	3	2	188	2	24	1	1	9
Dillon	0	0	2	195	3	114	0	0	1	79	1	12	0	0	6
Dorchester	0	0	4	352	7	405	2	50	2	134	1	80	0	0	11
Edgefield	0	0	2	120	0	0	0	0	1	25	1	40	0	0	6
Fairfield	0	0	4	262	1	20	0	0	0	0	3	128	0	0	2
Florence	1	24	1	827	21	719	3	71	7	1089	5	345	7	51	29
Georgetown	0	0	2	256	9	407	1	3	3	284	2	76	1	2	9
Greenville	1	30	9	1937	45	2607	12	278	11	1726	6	455	8	63	116
Greenwood	1	15	3	332	7	328	1	8	2	400	2	100	4	18	9
Hampton	0	0	19	104	3	28	0	0	1	32	0	0	0	0	3
Horry	1	36	8	824	17	1320	4	100	6	885	3	175	8	35	33
Jasper	0	0	1	88	1	93	3	76	1	41	0	0	1	2	2

Kershaw	0	0	2	24	7	132	1	8	1	119	1	30	2	10	5
Lancaster	0	0	3	280	3	234	2	15	2	274	1	60	1	1	10
Laurens	1	12	4	459	9	421	1	8	1	76	2	83	2	16	2
Lee	0	0	1	120	4	139	0	0	1	20	1	25	0	0	1
Lexington	1	30	9	1082	24	1556	4	70	3	637	7	663	7	75	36
McCormick	0	0	1	120	0	0	0	0	0	0	0	0	0	0	0
Marion	0	0	2	187	1	5	0	0	1	124	4	109	0	0	7
Marlboro	0	0	1	110	1	80	1	3	0	0	0	0	0	0	3
Newberry	0	0	2	264	2	80	0	0	1	90	1	15	1	11	2
Oconee	1	15	2	252	7	399	3	10	1	169	2	98	0	0	5
Orangeburg	0	0	4	383	20	365	2	17	2	301	4	154	3	5	14
Pickens	0	0	7	509	12	600	1	46	2	164	1	60			5
Richland	1	12	13	1938	57	1485	13	409	14	2509	7	343	5	29	67
Saluda	0	0	1	176	3	74	0	0	0	0	0	0	0	0	0
Spartanburg	1	15	16	1328	31	1512	5	126	6	935	2	120	2	13	26
Sumter	0	0	4	454	20	604	1	3	1	283	4	147	2	4	25
Union	0	0	2	201	2	64	0	0	1	143	2	45	0	0	1
Williamsburg	0	0	2	184	4	56	0	0	1	25	6	174	1	4	8
York	1	16	8	753	18	1186	4	27	2	338	5	219	9	17	
	13	287	196	20307	501	21520	84	1585	105	15148	100	4876	96	489	582

Red highlight indicates 50 or less beds for Nursing Home, Assisted Living & Adult Day Care in County. Also 1 or less In Home Care Companies



## *Appendix B. Glossary of Definitions (Source: Center to Advance Palliative Care)*

**Advanced Care Planning:** Conversations used as a means for patients, together with physicians and families, to establish goals of care for their future.

**Advanced Directives:** A written statement of a person's wishes regarding medical treatment, often including a living will, made to ensure those wishes are carried out should the person be unable to communicate them to a doctor.

**Allow for Natural Death (AND):** Allow natural death, is a legal order, written or oral depending on country, indicating that a person does not want to receive cardiopulmonary resuscitation if that person's heart stops beating. Sometimes it also prevents other medical interventions.

**Assisted Living Facility (ALF):** Housing for elderly or disabled people that provides nursing care, housekeeping, and prepared meals as needed.

**Do not Resuscitate (DNR):** Do Not Resuscitate, also known as no code or allow natural death, is a legal order, written or oral depending on country, indicating that a person does not want to receive cardiopulmonary resuscitation if that person's heart stops beating. Sometimes it also prevents other medical interventions.

**Executor of Estate:** An executor (or executrix) of an estate is an individual appointed to administer the estate of a deceased person. The executor's main duty is to carry out the instructions to manage the affairs and wishes of the deceased person's estate

**Hospice Care:** Typically a benefit to care for patients that are in the last months of life and who has decided to forgo any disease modifying treatments. It is the most holistic form of Palliative Care.

**Living Will:** A written statement detailing a person's desires regarding their medical treatment in circumstances in which they are no longer able to express informed consent, especially an advance directive.

**Long Term Care (LTC):** Long-term care generally refers to non-medical care (ie, custodial care) for patients who need assistance with basic daily activities such as dressing, bathing and using the bathroom.

**Serious Illness:** A health condition that carries a high risk of mortality and either negatively impacts a person's daily function or quality of life or excessively strains the caregiver.

**Skilled Nursing Facility (SNF):** A skilled nursing facility is a special facility or part of a hospital that provides medically necessary professional services from nurses, physical and occupational therapists, speech pathologists, and audiologists. This is for more complex sick patients that need more than custodial care.

### ***Appendix C. Palliative Care and Quality of Life Study Committee Members***

The Honorable Brad Hutto, Chair  
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Ms. Mary Gail Douglas, Vice Chair  
*SC Department on Aging Representative*

The Honorable Michael Rivers, Sr.  
*South Carolina House of Representatives*

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Mr. Gerry Dickinson  
*SC Department on Aging*

*In compiling this report, the Study Committee consulted with a number of organizations and state agencies; however, this report does not represent the official position of any organization or state agency. Any organization or state agency's consultation with the study committee does not represent an endorsement of the report issued by the committee.*

## ***Appendix D. Further Reading***

Center to Advance Palliative Care (CAPC)

<https://www.capc.org/>

DHEC Regulation 61-78: Standards for Licensing Hospices

<https://scdhec.gov/sites/default/files/docs/Agency/docs/health-regs/61-78.pdf>

Get Palliative Care (Public Awareness and Resources)

<https://getpalliativecare.org/>

H.R.3119 - Palliative Care and Hospice Education and Training Act (PCHETA)

<https://www.congress.gov/bill/114th-congress/house-bill/3119>

List of Current Inpatient and Outpatient Hospice Programs

<https://www.dhec.sc.gov/BHFL/hospice-licensing>

National Consensus Project Clinical Guidelines for Quality Palliative Care

[https://www.nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC-NCPGuidelines\\_4thED\\_web\\_FINAL.pdf](https://www.nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC-NCPGuidelines_4thED_web_FINAL.pdf)

National Hospice and Palliative Care Organization Facts and Figures Report

<https://www.nhpco.org/nhpco-releases-updated-edition-of-hospice-facts-and-figures-report/>

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