



Delaware End-of-Life Workgroup

FINAL REPORT AND

RECOMMENDATIONS

Presented to the

Delaware Health Care Commission

March 31, 2016

Preface

Delaware is in the midst of significant change with regard to healthcare and is seeking to transform the State's system of care so that it may better address patient needs and improve population health while achieving greater value by reducing per capita costs of healthcare. A key facet of this transformational work is an increasing emphasis on *person-centered care*, which involves engaging consumers in defining goals for their health and healthcare so that they may access care accordingly. Perhaps more than anything else, this concept of person-centered care is at the heart of the work that is reflected in this report.

Over the past several months, the End-of-Life workgroup solicited input from interested stakeholders via a series of meetings, public listening sessions and other communications. During the course of these interactions, a guiding principle emerged relative to the workgroup's efforts: *Every person must decide for him or herself*. The considerations surrounding palliative and end-of-life care reach far beyond the realm of medicine and include lifestyle preferences, family and community supports and faith/belief systems, among other things. Person-centered care seeks to empower the consumer by providing information and resources to facilitate a well-informed decision regarding care in consultation with one's team of care. Two individuals presented with the same information may come to very different conclusions about which course of action to pursue. Understanding and articulating preferences about care, including end-of-life care, is not about limiting options but rather providing clarity about one's wishes so that they may be honored even when the individual may be rendered incapable of communicating on his or her own behalf.

The reader is encouraged to keep this guiding principle in mind while reviewing the information and recommendations contained in the following pages. It is imperative that each individual have access to the information and resources that will enable decisions about care that best reflect personal goals and priorities and yield the right care at the right time. The recommendations in this report seek to further progress toward that aim and to better position Delaware to support the individual needs and preferences of Delawareans.

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I. Executive Summary

A growing consensus is emerging across the United States about the importance of end-of-life and palliative care and planning especially as it relates to honoring individual preferences and ensuring high quality care for individuals with serious illness and those nearing the end of life. In recognition of this fact and to consider options for improving awareness of and access to end-of-life and palliative care and resources in Delaware, the Delaware Health Care Commission (HCC) convened the End-of-Life Workgroup in November of 2015.

The assembling of the workgroup comes at a time when Delaware is in the midst of significant change related to healthcare delivery. Delaware's State Innovation Model (SIM) initiative seeks to refine the system of care with emphasis on person-centered care that achieves the 'triple aim' of improving the health of Delawareans, improving the patient experience of care, and reducing health care costs. Similarly, much of the workgroup's effort was based on the premise that *each person must decide* for him or herself, in coordination with the team of care, the course of action and care that best aligns with personal values and preferences relative to health and quality of life.

Over the course of approximately four months, the workgroup held five in-person meetings in Dover, conducted four public listening sessions statewide, researched effective models from other state and national programs and reviewed available data to better understand the current landscape of end-of-life and palliative care in Delaware, identify gaps in offerings and suggest actions that could be taken toward addressing unmet need. Throughout the process, public input was also solicited via a dedicated e-mail address and all materials developed by the workgroup were posted to a webpage accessible to the public. The workgroup benefitted significantly from robust public participation throughout the course of its efforts.

The end result of the workgroup's efforts was a set of recommendations grouped according to the specific areas of focus outlined by the HCC in its original charge to the HCC. Briefly, these included: 1) Consumer outreach, education and awareness; 2) Professional outreach, training, support and education; 3) Enabling access to palliative care services; and 4) Other recommendations. The workgroup was also charged with making a recommendation regarding the most appropriate governance structure for ongoing support and consideration of end-of-life issues in Delaware.

The overarching recommendation of the workgroup is the designation of an entity to coordinate all efforts related to palliative and end-of-life care in Delaware. Specifically, the group recommended that the Delaware End-of-Life Coalition (DEOLC) be approached to serve in this capacity and that funding be made available to the DEOLC to support the hiring of a full-time staff person. This allocation of resources would enable to DEOLC to bolster its current efforts and create a robust organization dedicated to promoting and sharing information related to end-of-life and palliative care offerings in Delaware.

Other key recommendations outlined in the report include the following:

- Formally link current activities related to end-of-life and palliative care with ongoing health system transformation efforts involving, at minimum, the DEOLC, Palliative Care Council of the Delaware Healthcare Association (DHA), the Delaware Health Care Commission (HCC) and the Delaware Center for Health Innovation (DCHI).
- Develop, implement and evaluate a Delaware-specific awareness campaign that engages an array of stakeholders and leverages the wealth of available resources in the state. An effective campaign will ideally include standardized materials and information geared toward a variety of audiences (patients, providers, caregivers, etc.), utilize technology and multiple platforms and be culturally sensitive.
- Specifically promote palliative and end-of-life care educational offerings as a means to meet continuing education requirements for providers at all levels.
- Support and monitor the growth of palliative and end-of-life care services offered in inpatient and community-based settings.
- Using resources compiled by the Delaware End-of Life Coalition as a basis, build and continue to update a compendium of resources related to end-of-life and palliative care for consumers, advocates, and service providers.
- Explore mechanisms to make patient wishes readily accessible in a variety of settings.
- Using existing data and data collection tools as a foundation, develop and implement a comprehensive, statewide approach to gathering and using data related to end-of-life and palliative care.

The full suite of workgroup recommendations may be found in Section V of this report.

The report also includes high level cost estimates related to implementing some of the key provisions outlined in the recommendations including the hiring of a full-time staff person for the DEOLC and the design and execution of a statewide awareness campaign focused on end-of-life and palliative care issues.

Delaware has made notable progress in recent years toward improving awareness of and access to end-of-life and palliative care. The findings and recommendations contained in this report are intended to serve as a roadmap to further progress toward comprehensive, person-centered care for all Delawareans particularly those dealing with serious or terminal illness.

II. Introduction

In November of 2015, the Delaware Health Care Commission (HCC) approved the convening of a specialized workgroup focused on examining end-of-life and palliative care issues in Delaware. Recognizing an increasing awareness of and willingness to discuss end-of-life and palliative care and the role of these services in improving the quality of life for seriously and terminally ill individuals, the HCC identified a group of individuals with particular expertise on the subject and tasked them with the following:

- Review relevant recommendations and reports, including the Institute of Medicine Quality End of Life Care recommendations, Center to Advance Palliative Care 2015 Report, America's Health Rankings Senior Report, recently enacted Delaware Medical Orders for Scope of Treatment (DMOST) legislation and associated regulations, other relevant federal and state statutes and regulations, work and resources of Delaware End-of-Life Coalition, Center for Medicare and Medicaid Innovation and State Innovation Model work and resources, the Delaware Health Care Association's Palliative Care Council and other relevant information in order to broaden the understanding of palliative care and end-of-life care issues and prioritize potential areas for recommendations.
- Identify key End-of-Life care issue areas, including advance care planning.
- Develop recommendations and options for consideration regarding:
 - Consumer outreach, awareness and education activities regarding palliative and end-of-life care and planning, including advanced care planning and the recently enacted DMOST legislation;
 - Professional outreach, training, support and education concerning the care of those with serious chronic and life-threatening conditions;
 - Enabling access to palliative care services and supporting the capacity in the health care system to provide palliative care services in home, community, hospice, skilled nursing facilities, hospital and any other relevant settings;
 - Other recommendations to support comprehensive health care services to Delawareans suffering from advanced and serious illnesses.
- Make recommendations regarding the most appropriate governance structure for ongoing support and consideration of end-of-life issues in Delaware.
- Issue report to Delaware Health Care Commission providing recommendations and options on or before April 1, 2016.

This report represents the culmination of the workgroup's activities to date and includes relevant information and recommendations pertaining to the above specified areas. A full list of the end-of-life workgroup membership is included as Appendix A.

Perhaps equally important to stating the workgroup's charge is identifying issues that were not directly within its scope but frequently surfaced in discussions and feedback received:

- Cost, and particularly the potential for palliative and end-of-life care to reduce healthcare spending, was not an explicit focus of workgroup efforts. While numerous sources indicate that the application of palliative care, particularly at the end of life, may yield cost savings (by avoiding unnecessary and unwanted hospitalizations, for example), the workgroup was not tasked with exploring this in detail. Rather, the intent was to determine what a model system of palliative and end-of-life care and supports for Delaware would look like and identify actionable items for achieving it.
- *Physician aid in dying*, while understandably associated with end-of-life issues, was also outside of the workgroup's purview. While many interested stakeholders shared personal

perspectives on this subject in meetings and public listening sessions, it is important to clarify that the group has not been tasked with making any recommendations on this issue.

The workgroup received feedback about several other items that may be considered tangential to its efforts but, due to the limitations of scope, are not addressed in this report. These items include issues and considerations regarding grief and bereavement, organ donation and access to medical marijuana for pain management, among others. Feedback not directly related to the scope of this report has nonetheless been documented and made available to interested stakeholders.

III. Background

The decision of the Delaware Health Care Commission (HCC) to convene a workgroup specifically focused on end-of-life and palliative care in the fall of 2015 reflected a number of factors including the following:

- Increasing prevalence of palliative care and understanding of its role in improving quality of care and patient and family engagement
- Growing emphasis on person-centered care
- Aging population and increased prevalence of people living longer with serious illness
- Greater willingness to discuss issues related to death and dying
- Recent initiatives related to palliative care and end-of-life planning

In Delaware and nationally, efforts are underway to engage consumers, providers and other stakeholders in meaningful conversations about the provision and receipt of healthcare, including as it relates to personal goals and preferences and quality of life considerations.

Defining Palliative and End-of-Life Care

It is important to distinguish between palliative, hospice and end-of-life care. While interrelated, the terms are not interchangeable and understanding the distinctions among them provides helpful context when reviewing the information and recommendations in this report. Below are definitions of each term that have been adopted from established sources; among many available definitions for each term, these are the ones deemed most relevant to this workgroup's purposes.

Palliative medicine is specialized medical care for people with serious illnesses. It focuses on providing relief from the pain, symptoms and distress of serious illness. It is a team-based approach to care involving specialty-trained doctors, nurses, social workers and other specialists focused on improving quality of life. By determining patients' goals of care through skilled communication, treating distressing symptoms and coordinating care, palliative care teams meet patients' needs and help them avoid unwanted and expensive crisis care. Unlike hospice care, palliative care can be provided *at the same time* as curative treatments; it is appropriate at any

age and at any stage of a serious illness.¹ Palliative care is focused on improving quality of life and does not intend to either prolong living beyond what is natural or hasten death.

The explicit note about palliative care being appropriate at any stage is important because it recognizes that anyone, including young children, with serious illness may benefit from receiving palliative care. The needs of pediatric patients and their families differ in many ways from those of adults. Specific organizations and programs have been developed to address these needs; these will be acknowledged in greater detail later in this report.

Figure 1. The below graphic illustrates the intersection of palliative, end-of-life and hospice care.



End-of-Life Care is care that helps those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.² End-of-life care is often but not always delivered through hospice.

Hospice: Considered to be the model of quality, compassionate care for people facing life-limiting illness or injury, hospice care involves a team-oriented approach to medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is provided to the patient's loved ones as well. At the center of hospice and palliative care is the belief that each person has the right to die pain-free and with dignity, and that families will receive the necessary support to allow this to occur³. Hospice also provides bereavement support after death occurs.

At present, little distinction exists between end-of-life and hospice care in Delaware because end-of-life care is provided almost exclusively through hospice. However, a future model for end-of-life care in Delaware envisions the provision of and funding for end-of-life care via models including but not limited to hospice.

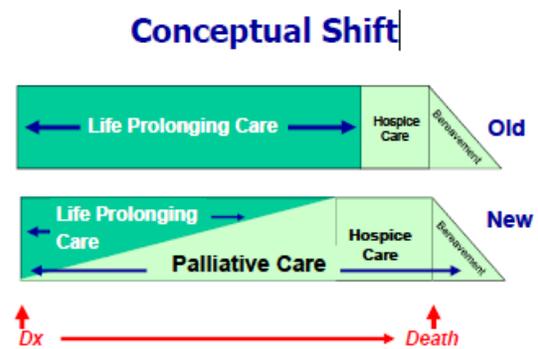
¹ *America's Care of Serious Illness*. Center to Advance Palliative Care, 2015. <https://reportcard.capc.org/wp-content/uploads/2015/08/CAPC-Report-Card-2015.pdf>

² *Commissioning End of Life Care*. The National Council for Palliative Care, 2011. <http://www.ncpc.org.uk/sites/default/files/AandE.pdf>

³ National Hospice and Palliative Care Organization. <http://www.nhpco.org/about/hospice-care>

Palliative and hospice care are a part of a continuum of care that begins with life prolonging care and shifts to emphasizing comfort care when the patient has a prognosis of six months or less to live. Figure 2 at the right⁴ illustrates a conceptual shift from focusing solely on life prolonging care up to the point at which the patient shifts to hospice care, to gradually introducing and increasing palliative care concurrent with life prolonging care until such time as the patient is ready for hospice care. The 'New' model in Figure 2 represents a more desirable approach to patient care as it enables the patient to have access to comfort care while receiving life prolonging treatments until such time as those treatments are no longer appropriate or beneficial. Thus, the patient is not required to wait for life prolonging treatments to stop in order to begin experiencing the benefits of palliative and/or hospice care.

Figure 2. Old versus new model of transitioning patients to palliative and hospice care



Increasing prevalence of palliative care and understanding of its role in improving quality of care and patient and family engagement

Recent years have shown a steady increase in the availability of palliative care offerings across the U.S., particularly in, but not limited to, hospital and acute care settings. While elements of palliative care have been offered through various channels in the past, public demand and increased focus on value and outcomes in care are driving an increasing number of healthcare systems to formally develop and promote palliative care programs. In its 2015 report card, the Center to Advance Palliative Care discovered that 67 percent of U.S. hospitals with fifty or more beds report palliative care teams, up from 63 percent in 2011 and 53 percent in 2008.¹

On the state level, the Delaware Healthcare Association's Palliative Care Council has noted that 83% of Delaware non-profit hospitals surveyed have a palliative care program in place. Additionally, all hospitals plan to increase palliative care components within the next 3 years, especially the number of staff, provider education offerings and funding or budget increases. One-third indicated they may establish an outpatient palliative care program within 3 years. Targeted support for these efforts and capacity building among providers in Delaware could better meet the palliative care needs of the community, especially given the significant aging trend of the Delaware population as described below.

Palliative care produces significant improvements in clinical outcomes. These include relief from pain and symptoms, less anxiety and depression, and improved quality of life for patients and their families.¹ Statistical analysis to support these claims is emerging while a body of recently published studies, articles and books offer a wealth of information, including firsthand accounts,

⁴ National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care. 2nd ed. Pittsburgh, PA: National Consensus Project for Quality Palliative Care; 2009:6.
<http://www.nationalconsensusproject.org/Guidelines.pdf>

about the role of palliative care in improving both outcomes and experience of patients and families.

A recent editorial published by the American Academy of Family Physicians suggests that despite documented benefits, palliative care is underutilized in the management of advanced or terminal illnesses and identifies a number of barriers to its use including confusion about terminology, uncertainty of prognosis, mistrust of health care professionals and psychology of decision making.⁵ Other barriers to palliative care cited in the Center to Advance Palliative Care's 2015 report card include workforce, research and payment models. All of these barriers must be considered in determining how best to improve understanding of and access to palliative care services.

Growing emphasis on person-centered care

The healthcare landscape in the United States is changing rapidly with an increasing focus on person-centered, value-based care that addresses patient needs while seeking to reward quality, results-oriented care rather than quantity of services provided. Central to this approach is the premise that consumers armed with information and tools for engaging in their health and related decisions will be empowered to receive the care they desire and more likely to achieve intended healthcare outcomes. For patients dealing with serious or terminal illness, understanding the complexities of their conditions and the risks and benefits associated with treatment options is important to making informed decisions about the nature and extent of treatment they wish to pursue. By working closely with care team members and leveraging their medical expertise while considering personal goals and preferences, the patient is empowered to make the decisions right for him or herself.

Delaware is preparing to implement significant changes with regard to how providers deliver and are reimbursed for medical care. Delaware's State Innovation Model (SIM) initiative, under the direction of the recently formed Delaware Center for Health Innovation (DCHI) seeks to refine the system of care with emphasis on person-centered care that achieves the 'triple aim' of improving the health of Delawareans, improving the patient experience of care, and reducing health care costs. At the core of this initiative is the premise that an informed consumer in a coordinated system of care has an increased likelihood of being an active participant in his or her care and therefore receiving the healthcare that he or she wants and needs.

A recurring theme in this workgroup's discussions was the idea that every person must decide for him or herself about goals and preferences related to health and quality of life, which reflects a shift toward a person-centered approach to healthcare decisions.

Aging population and increased prevalence of people living longer with serious illnesses

People in the United States are living longer than ever before – according to a 2014 study by the Centers for Disease Control and Prevention, the average life expectancy in the U.S. has increased

⁵ "Editorial: Palliative Care: Benefits, Barriers and Best Practices." *American Family Physician*. Volume 88, Number 12. December 15, 2013.

to 78.8 years, the longest ever recorded.⁶ The percentage of the population aged 65 and over is steadily increasing: among the total population this group represented 13.0 percent in 2010 and is projected to reach 20.9 percent by 2050. Delaware's elderly population is growing at a very rapid rate. From 2000 – 2010, the number of Delawareans aged 65 and over grew by 27.1%, the 11th fastest growth rate in the country. During the same time period the number of Delawareans aged 85 and older grew by 49.2%, which is the 5th fastest growth rate in the country.⁷

Improvements in medicine have certainly impacted this increase in life expectancy including the development and refinement of treatments and technology that may be used to sustain life, including when a curative treatment is not an option. To that end, individuals living with serious conditions such as heart disease, diabetes, cancer, obesity or arthritis have treatment options and supports that did not exist a decade ago that may enable a longer and higher quality of life. As of 2012, about half of all adults—117 million people—had one or more chronic health conditions. One of four adults had two or more chronic health conditions.⁸

The increase in life expectancy has prompted a great deal of discussion about quality of life, particularly in recent years. In the United States, an increased emphasis on living longer has in many cases led to a significant decline in quality of life, particularly for older Americans. While emphasizing the importance of personal preferences when it comes to making healthcare decisions, many have suggested that particular consideration be given to quality of life in addition to longevity. Advance care planning tools including advance directive forms can help to shape thoughts concerning these issues and facilitate often difficult conversations with loved ones about them.

Advance care planning refers to an ongoing process of discussing and clarifying the current state of a person's goals, values and preferences for future medical care.⁹ The result of advance care planning is often an **advance care directive**, which generally refers to a written document to direct future medical care in the event that a person loses capacity to make health care decisions (i.e., becomes incapacitated). An advance care directive may be completed by any person at any stage of life and may be updated over time to reflect changing care preferences. Delaware's advance directive form may be accessed at <http://www.dhss.delaware.gov/dsaapd/advance1.html>.

Greater willingness to discuss issues related to death and dying

In his book, *Being Mortal*, Dr. Atul Gawande explains an inherent challenge of meeting patient needs and providing the right care at the end of life: in America, people are traditionally reluctant

⁶“CDC: Life Expectancy in the US Reaches Record High.” *Medical News Today*. October 8, 2014.

<http://www.medicalnewstoday.com/articles/283625.php>

⁷“65+ in the United States: 2010.” West, Loraine et al. June 2014.

<http://www.census.gov/content/dam/Census/library/publications/2014/demo/p23-212.pdf>

⁸“Chronic Diseases: The Leading Causes of Death and Disability in the United States.” *Centers for Disease Control and Prevention*. <http://www.cdc.gov/chronicdisease/overview/#ref1>

⁹“Terms and Definitions.” Honoring Choices Massachusetts.

<http://www.honoringchoicesmass.com/resources/glossary/#sthash.NnsoHaQe.dpuf>

to discuss death and dying. He applies this observation to patients, loved ones and even physicians and suggests that this reluctance frequently leads patients to undergo medically ineffective treatments at the end of life that have little or no impact on health outcomes or quality of life.¹⁰ Indeed, workgroup meetings and public listening sessions reinforced the perspective that conversations about death are generally considered uncomfortable at best and often taboo among many individuals and communities.

While advance care directives are considered to be an important tool in ensuring that an individual receives the medical care that he or she desires – particularly at the end of life - an estimated 75 percent of Americans have never taken the time to discuss their wishes or provided any written guidance to loved ones or healthcare providers in the event they are unable to speak for themselves.¹¹ Frequently cited reasons for this include a lack of familiarity with the advance directive form or how to complete it, a perception that the form is only used to limit care and the belief that advance care planning is pertinent only to the elderly and seriously ill.

Recently, however, a growing willingness to discuss issues of death and dying has emerged in the U.S. and is supported by many high profile initiatives, some newer and others well established, working to normalize these discussions and promote advance care planning. Of the high profile examples viewed as particularly effective models worthy of replicating or incorporating elsewhere, Respecting Choices may be the most well-known. Respecting Choices is a nationwide advance care planning model that originated in La Crosse, Wisconsin and has since developed into a program that offers nationwide conferences and has been adapted by communities across the country. As a result of the original initiative, approximately 96 percent of people who die in La Crosse have an advance care directive (in contrast to national estimates of roughly 20-30% of the population.) Other prominent national programs include The Conversation Project, which offers tools and resources to facilitate discussions about end-of-life preferences, and the Five Wishes initiative, whose advance care planning tool is used in all 50 states as well as other countries and is available in 28 languages and Braille. The success of and interest in these initiatives also underscores the importance of Delaware opting to further explore these issues at this time.

Recent Initiatives Related to Palliative and End-of-Life Care

Several other recent initiatives highlight the importance of palliative and end-of-life care considerations at this point in time:

- **Medicare reimbursement for advance care planning:** As of January 1, 2016, Medicare now offers reimbursement to certain providers for having advance care planning sessions with patients and their families to discuss end-of-life preferences. Providers are permitted to bill for multiple sessions with a patient.

¹⁰ Gawande, Atul. *Being Mortal*. New York: Metropolitan Books, 2014.

¹¹ Kottkamp, Nathan, Esq. "The Importance of Advance Health Planning." *Delaware Journal of Public Health*, January 2016. <http://issuu.com/dam-dpha/docs/final-de-jph-january>

- **Medicare Care Choices pilot:** Beginning in 2016, the Centers for Medicare & Medicaid Services (CMS) will provide a new option for Medicare beneficiaries to receive hospice-like support services while concurrently receiving curative care. CMS will evaluate whether providing these supportive services can improve the quality of life and care received by Medicare beneficiaries, increase patient satisfaction, and reduce Medicare expenditures. Delaware Hospice has been selected to participate in the pilot.
- **Medicare Choices Empowerment and Protection Act:** Senator Coons has proposed this legislation to encourage Medicare beneficiaries to complete an electronic advance directive by offering a modest financial incentive for doing so. The advance directive may be modified or cancelled at any time.
- **Concurrent Care for Children Requirement (CCCR):** The Patient Protection and Affordable Care Act (ACA), signed into law in 2010, included a provision requiring state Medicaid agencies to pay for both curative/life prolonging treatment and hospice services for children under age 21 who qualify. The provision was designed to address the fact that previously parents in all but a few states were faced with forgoing curative/life prolonging treatments for their children to be eligible for hospice services.¹²
- **End-of-Life Roundtable:** Senator Coons also recently convened an end-of-life roundtable bringing together experts and interested stakeholders to discuss ideas for improving end-of-life care in Delaware.
- **Delaware Medical Orders for Scope of Treatment (DMOST):** In May of 2015, House Bill 64 (the DMOST Statute) was passed and signed into law by Governor Markell with an effective date of April 1, 2016. DMOST is designed to improve the quality of care people receive at the end of life by translating patient/resident goals and preferences into medical orders. DMOST is based on communication between the patient/resident, Health Care Agent or other designated decision-maker and health care professionals that ensures informed medical decision-making.

Honoring patient preferences is a critical element in providing quality end-of-life care. To enable physicians and other health care providers to discuss and convey a patient's wishes regarding cardiopulmonary resuscitation (CPR) and life-sustaining treatment, the DMOST coalition worked to create statute and regulations that can be used statewide by health care providers and facilities as the legal equivalent of an inpatient Do Not Resuscitate (DNR) form.

DMOST is intended to provide a single document that will function as an actionable medical order and could transition with a patient through all health care settings. It is intended that the form will be transported with the patient between different health care settings in order that their wishes for life-sustaining treatment and CPR will be clearly indicated.

¹² *Concurrent Care for Children Implementation Toolkit*. District of Columbia Pediatric Palliative Care Collaboration and National Hospice and Palliative Care Organization.
http://www.nhpco.org/sites/default/files/public/ChiPPS/CCCR_Toolkit.pdf

- **Palliative Care Council:** The Delaware Healthcare Association convened a Palliative Care Council (PCC) in 2013 with a focus on increasing palliative care awareness and availability around the state, especially in Delaware's acute health care systems. The PCC recently conducted a survey of its member hospitals to collect information about palliative care offerings and identify opportunities for growth and barriers to implementation. Next steps are expected to include identifying and defining standards and metrics for inpatient care and determining whether standards are being met, documenting best practices and surveying third party payers and Medicaid about reimbursement.

III. Approach

This section outlines the workgroup's approach to conducting research, facilitating meetings, and collaborating with key players and subject matter experts from across the state.

Summary of Workgroup Meetings and Coordination Activities

The workgroup conducted five meetings in Dover, centrally located to encourage maximum participation from consumers across the state. The workgroup began its work by reviewing goals and objectives, considering recent developments in Delaware and nationally regarding end-of-life and palliative care, and discussing useful resources including findings and best practices related to these issues. Subsequent activities included reviewing available end-of-life data from the Delaware Health Statistics Center, Centers for Disease Control and Prevention, and the Delaware Healthcare Association's Palliative Care Council Survey; discussing key themes gleaned from workgroup and public listening sessions; reviewing and discussing opportunities for alignment with the State Innovation Model work; and developing the format and content of this report.

In addition to the committee members (whose organizational affiliations are included in Appendix A), the workgroup collaborated with a number of key players and subject matter experts during these meetings. Individuals from the following organizations provided valuable insights into our work:

- Delaware Department of Health and Social Services
 - Division of Public Health
 - Division of Services for Aging and Adults with Physical Disabilities
- Delaware Nurses Association
- Delaware Department of Insurance
- Developmental Disabilities Council
- Center for Disabilities Studies, University of Delaware
- Delaware Resources Board
- Office of Senator Chris Coons
- Bayhealth Medical Center
- Beebe Healthcare
- League of Women Voters

- State Council for Persons with Disabilities
- United States Department of Veterans Affairs
- Delaware Nurses for Life
- Wilmington University
- Nemours
- American Cancer Society Action Network, Inc.
- Gift of Life Donor Program

Research Conducted to Date

The Health Care Commission charged the End-of-Life Workgroup with reviewing relevant recommendations and reports in order to broaden the understanding of palliative care and end-of-life care issues and prioritize potential areas for recommendations. Workgroup efforts were supported tremendously by a vast array of resources devoted to these issues. The table below, while not exhaustive, identifies several key resources referenced by the workgroup and summarizes key findings of each. A more extensive Annotated Bibliography of Resources may be found at the End-of-Life workgroup's [website](#) and is included in this report as Appendix B.

Resource	Summary of Findings
Institute of Medicine (2014). <i>Dying in America, Improving Quality and Honoring Individual Preferences Near the End of Life</i>	This report from the Institute of Medicine (IOM) provided guidance to the workgroup and helped inform the development and structure of this report. In <i>Dying in America</i> , a consensus report from IOM, a committee of experts finds that improving the quality and availability of medical and social services for patients and their families could not only enhance quality of life through the end of life, but may also contribute to a more sustainable care system.
Center to Advance Palliative Care, National Palliative Care Research Center (2015). <i>America's Care of Serious Illness, 2015 State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals.</i>	This report provides analysis of whether seriously ill patients in the United States are receiving equitable access to palliative care services in hospitals. The goal is both to inform and to help the public and policymakers increase the availability of palliative care for the millions of Americans in need. Delaware received a B on the report card, indicating that 75% state's hospitals report the presence of a palliative care team.
Delaware Advance Health Care Directive Form	An Advance Health Care Directive is a document that allows mentally competent adults the opportunity to give advance instructions for medical or surgical treatment that they want or do not want. Individuals can complete the form at any time and should give copies to their doctor, agent, spouse, family members, and close friends. This will help explain to each person who receives a copy of their health care directive what choices they made on the form, and why.
DMOST Legislation – Delaware House of Representatives 148th General Assembly, Bill No. 64	Text of the Delaware Legislative bill passed in May 2015 regarding the Delaware Medical Orders for Scope of Treatment (DMOST) program, which is designed to improve the quality of care people receive at the end of life by translating patient/resident goals and preferences into medical orders. DMOST is intended to provide a single document that will function as an actionable medical order and could transition with a patient through all health

Resource	Summary of Findings
	care settings. It is intended that the form will be transported with the patient between different health care settings in order that their wishes for life-sustaining treatment and CPR will be clearly indicated. The medical order forms resulting from this legislation will be available in Delaware as of April 1, 2016.
Palliative Care Council Survey	This survey was conducted by the Delaware Healthcare Association in 2015 and distributed to all non-profit hospitals in the state. Five of six respondents reported having a palliative care (PC) program; one respondent had none. The workgroup determined through its review of survey responses that all hospitals plan to increase PC components within the next 3 years, especially the number of staff, provider education offerings and funding or budget increases. One-third indicated they may establish an outpatient PC program within 3 years. Finally, a key takeaway uncovered through the survey was that the most common challenge to offering PC reported by hospitals was a lack of knowledge about PC programs among patients and family (83%).
Five Wishes	Five Wishes is an easy-to-use legal document written in everyday language that lets adults of all ages plan how they want to be cared for in case they become seriously ill. Available in 28 languages and Braille, Five Wishes helps adults express how they want to be treated if they are seriously ill and unable to speak for themselves. All Five Wishes documents are legally valid in most states and can be obtained at any one of Delaware's six Federally Qualified Health Centers.
The Conversation Project	The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care. Their website includes a Starter Kit for individuals and families interested in initiating conversation with their loved ones about how they want the end of their lives to be. The Conversation Project also has a Resource Center page on their website with a number of tools for individuals and families to use and share with one another.

Review and Analysis of Available Data

The End-of-Life workgroup collected and analyzed available data in an effort to better understand the context and trends related to end-of-life and palliative care offerings and issues in Delaware and nationally. Because quantitative data in this area is somewhat limited (for example, no reliable data exists regarding the percentage of Americans with advance care directives), the majority of data analyzed was qualitative. Data sources consulted in the development of report findings include:

Delaware Health Statistics Center Vital Statistics: The Delaware Health Statistics Center provides public use data on an annual basis indicating the cause and location of deaths that occur in the state. This enabled discussion about where people die in Delaware - inpatient setting, an outpatient (emergency room) setting, nursing home, individual's residence or other. Included within the 'other' category is hospice, which for the 2011 data represented approximately 85

percent of ‘other’ and thus is the main driver of the spike in percentage of deaths in the ‘other’ setting.

Centers for Disease Control and Prevention (CDC): The CDC data captures place of death over time, similar to the above referenced data, for the United States. This data allowed the workgroup to compare Delaware-specific data against national trends to gauge progress.

Death Location*	2001	2006	2011	Pct. Change	U.S.**
Inpatient	40.27%	33.95%	29.29%	-27.27%	36%
ER – Outpatient	8.89%	7.87%	7.07%	-20.47%	7%
Dead on Arrival	0.63%	0.41%	0.31%	-50.79%	
Status Unknown	0.05%	0.35%	N/A	N/A	
Nursing Home	18.34%	20.97%	17.52%	-4.47%	21.7%
Residence	27.56%	27.95%	30.19%	9.54%	25.4%
Other	4.26%	8.48%	14.25%	234.5%	
Not Classifiable	0.00%	0.03%	1.38%	N/A	
All Other	N/A	N/A	N/A	N/A	9.9%

* Source: http://www.dhss.delaware.gov/dhss/dph/hp/bthsdths_pubdata.html

**Based on 2007 figures, the most recently available data. Source: CDC Data, *Place of Death, Over Time: United States, 2007.*

Both Delaware and national data showed a steady downward trend in the number of individuals dying in hospitals and a sharp increase in the number dying in hospice, which likely reflects the increased availability of hospice services over the past decade.

Delaware Healthcare Association’s Palliative Care Council Survey: Conducted in 2015, surveys were distributed to all non-profit hospitals in Delaware with a 100% response rate. This data provided a number of key findings which include, but are not limited to:

- Five of six respondents reported having a palliative care program; one respondent had none. While all hospitals with palliative care programs are tracking the number of patients encountered and disposition at discharge, less than half are currently measuring satisfaction with palliative care services.
- All hospitals plan to increase palliative care components within the next 3 years, especially the number of staff, provider education offerings and funding or budget increases. One-third indicated that they may offer an outpatient palliative care program within 3 years.
- The most common challenge to offering palliative care reported by hospitals was a lack of knowledge about these programs among patients and family.

Due to a general scarcity of Delaware-specific data related to palliative and end-of-life issues, the workgroup has offered recommendations for gathering such information in the future to further inform efforts on these topics.

Statewide Listening Sessions

The workgroup facilitated four public listening sessions across the state encouraging Delawareans to share personal experiences and perspectives to help shape the future of end-of-life care. Attendees joined workgroup members for a discussion about palliative care, hospice care, advance care planning and related issues. All members in attendance were invited to

actively participate in the listening sessions by sharing their thoughts about palliative care and end-of-life issues. Key themes and observations from these listening sessions were discussed at length during the workgroup's February 12 meeting. The feedback from these listening sessions were instrumental in the development of the workgroup's recommendations documented in this report and a summary of listening session key themes included as Appendix D of this report.

Public Comment and Input

A high level of participation and input provided to the workgroup by the interested public significantly aided its efforts to understand the issues and considerations around end-of-life and palliative care and to develop this report. In addition to verbal input from those who attended workgroup meetings and listening sessions, written comments submitted via e-mail were received from more than a dozen individuals and organizations in response to the draft report and other materials, adding a welcome contribution of useful feedback and supplemental resources.

IV. Findings and Recommendations

This section presents the findings uncovered as a result of the workgroup's efforts and offers associated recommendations, grouped according to each of the key areas for which the workgroup was tasked with developing recommendations:

- Consumer outreach, awareness and education activities regarding palliative and end-of-life care and planning, including advance care planning and the recently enacted DMOST legislation;
- Professional outreach, training, support and education concerning the care of those with serious chronic and life-threatening conditions;
- Enabling access to palliative care services and supporting the capacity in the health care system to provide palliative care services in home, community, hospice, skilled nursing facilities, hospital and any other relevant settings;
- Other recommendations to support comprehensive health care services to Delawareans suffering from advanced and serious illnesses; and
- Recommendations regarding the most appropriate governance structure for ongoing support and consideration of end-of-life issues in Delaware.

Below are key findings and recommendations associated with each of the above areas, beginning with recommendations regarding the governance structure. In developing and discussing the full set of recommendations, workgroup members determined that the recommendations related to governance would likely provide the framework in which most of the other recommendations would be carried out and thus needed to be featured prominently in this section of the report.

Recommendation regarding the most appropriate governance structure for ongoing support and consideration of end-of-life issues in Delaware

Chief among the recommendations is the designation of an entity to coordinate all efforts related to palliative and end-of-life care in Delaware. Many organizations are already performing

services in this arena including direct provision of palliative and hospice care, counseling and social supports, advance care planning and public education and awareness. However, the absence of a particular body with responsibility for tracking and synchronizing these activities increases the likelihood that consumers, providers and others will struggle to access resources in an efficient manner.

Hence, the recommendation that sets the stage for more specific recommendations to follow is that Delaware designate an organization – specifically, the Delaware End-of-Life Coalition (DEOLC) – to serve as the go-to entity for information and resources related to palliative and end-of-life care in the state. The mission of the DEOLC is well aligned with the recommendations outlined in this report as are many of its existing programs and activities. It is recommended that Delaware formally approach the DEOLC to consider this designation with the understanding that changes to the DEOLC’s organizational structure and operations will be required to facilitate broader engagement and scope of activities. As a model for how to design a comprehensive and well-coordinated effort, it is recommended that Delaware look closely at California’s Coalition for Compassionate Care.

As the DEOLC currently employs no paid staff and has a very small operating budget, this designation will require the allocation of resources to fund a full-time staff person to perform these coordination activities and to support related initiatives. The suggested time frame for full implementation of this recommendation from the time of this report is no later than September 30, 2016.

In the interim, it is recommended that a subset of the workgroup continue to coordinate under the auspices of the HCC and that to the extent possible, the HCC continue to provide in-kind resources and administrative staff support for these efforts. The primary focus of the subgroup’s efforts during this period will be conducting planning related to the transition, including setting priorities and identifying resources and additional stakeholders to support it. The subgroup will also continue to develop the statewide campaign regarding public awareness of palliative and end-of-life care in order to sustain momentum on this important initiative.

Recommendation	Responsible Party
1. Formally designate the Delaware End-of-Life Coalition (DEOLC) to serve as the coordinating body for information and resources related to palliative and end-of-life care in Delaware and identify appropriate financial resources to support staffing and other related costs.	HCC, DEOLC
2. Formally link current activities related to end-of-life and palliative care with ongoing health system transformation efforts involving, at minimum, the DEOLC, Palliative Care Council of the Delaware Healthcare Association (DHA), the Delaware Health Care Commission (HCC) and the Delaware Center for Health Innovation (DCHI).	DEOLC, DHA, HCC, DCHI
3. Keep primary responsibility for implementation and monitoring of the recommendations contained in this report with the HCC until formal linkages are in place as outlined above.	HCC

Consumer outreach, awareness and education activities regarding palliative and end-of-life care and planning, including advanced care planning and the recently enacted DMOST legislation

The need for education and outreach to consumers regarding palliative and end-of-life care issues was underscored in every workgroup meeting and public listening session. Frequent issues that surfaced include confusion about the distinctions between different advance planning tools, lack of clarity surrounding palliative care offerings and benefits, concern about the taboo surrounding discussion of death and dying and consumer fears about being pushed toward treatment decisions that may not align with their personal values or preferences.

It is clear that a comprehensive outreach campaign must target more than those consumers dealing directly with issues related to palliative or end-of-life care (e.g. those undergoing or expected to undergo treatment themselves). The universe of parties involved in making decisions and providing support on these issues goes far beyond the impacted individual and may include family members and loved ones, caregivers, guardians, healthcare and social service providers, faith community representatives and many others. In order for a campaign to recognize its full potential in addressing consumer needs, the specific concerns and perspectives of all parties must be taken into account and any resources developed should be mindful of the particular needs and communication preferences of its intended audience.

KEY FINDING: Significant variation exists across Delaware in the quality and availability of end-of-life and advanced care planning resources designed for use by the general public.

- ❖ **Public education and engagement about end-of-life care issues is needed for a variety of audiences involved in decision making.** As noted above, beyond the patient, recommended audiences for communication include families, caregivers, guardians, providers and other trusted parties. Taking into account the needs and perspectives of loved ones and those responsible for making decisions on behalf of patients is considered

imperative to most effectively meeting patient needs and goals. Participants emphasized the need for education about what it means to have decision making power for loved ones and pointed out the difficulty of trying to understand this in the midst of a crisis. The particular needs of individuals with disabilities must also be considered, especially as these individuals may struggle to be heard when others think they know what is best for them.

- ❖ **Consumers are confused about the distinctions among forms and definitions related to end-of-life and palliative care.** Consumers offered a number of questions about the specific purpose, intended audience and powers associated with planning tools including advance care directives, living wills and the Delaware Medical Orders for Scope of Treatment (DMOST) form. Additionally, many individuals are unclear about the distinction between palliative and hospice care when approaching the end of life and the benefits of hospice care and the fact that it can, and often is, provided in the home setting.
- ❖ **Many consumers believe that creation of an advance care directive or completion of a DMOST form requires limiting options for life-saving measures.** Consumers expressed concern that filling out an advance directive or DMOST form meant consenting to forgo life-saving measures in the event of a serious medical incident. This misperception likely poses a very significant barrier to more widespread completion of advance directives.
- ❖ **Cultural sensitivity is extremely important in addressing and discussing the considerations and options around end-of-life care with different audiences.** In many communities and individual families, there continues to be a ‘taboo’ attached to discussions about death and dying and thus a need exists to normalize conversations around this topic. These cultural dynamics also exist and must be addressed among health care providers.
- ❖ **Delaware has many existing resources that may be utilized to support a public awareness campaign.** Several organizations in Delaware are already actively offering and promoting resources related to end-of-life and palliative care, including the Delaware End-of-Life Coalition and the state’s hospices, hospitals and provider community. Suggestions of other resources that might be leveraged to support a widespread awareness campaign include senior and community centers, faith-based communities, providers of legal services, Federally Qualified Health Centers and Meals on Wheels, among others. In addition, significant work has been done by numerous stakeholders related to the development and implementation of DMOST; Delaware could leverage information and lessons learned from that work in developing this campaign.
- ❖ **Several well-established national programs and initiatives offer useful resources for Delaware to leverage in developing a state-specific campaign.** Resources to which participants regularly referred include Five Wishes, Respecting Choices, The Conversation Project and Compassion and Choices as well as the Institute of Medicine’s Dying in America report and its comprehensive recommendations regarding end-of-life care. These are a few prominent examples of the extensive array of organizations and

material available for consideration and possible adaptation in Delaware. Tailoring well designed resources from other sources may enable more cost effective campaign development for Delaware.

Recommendation	Responsible Party
<p>1. Develop, implement and evaluate a Delaware-specific awareness campaign that engages an array of stakeholders and leverages the wealth of available resources in the state. The campaign should be formally aligned with the work of the DCHI’s Healthy Neighborhoods and Patient and Consumer Advisory Committees and include, at minimum, the following elements:</p>	<p>HCC/ DEOLC/DCHI</p>
<p>a. Standardized educational materials about palliative and end-of-life care disseminated through multiple channels</p>	
<p>b. Formal encouragement and support to civic and faith-based leaders, state agencies, the legal community, community organizations etc. to engage their constituents and provide fact-based information about palliative and end-of-life options, using appropriate media and other channels</p>	
<p>c. Input and guidance from relevant stakeholders to ensure that information about palliative and end-of-life care is developed and shared in a manner that is tailored to meet individual abilities, linguistically appropriate and culturally sensitive</p>	
<p>d. Use of new and existing tools, forms and mobile applications</p>	
<p>e. Emphasis on the role of palliative care in improving quality of life whether individuals are seriously and/or terminally ill</p>	
<p>f. Specific support and resources for those who may have responsibility for carrying out end-of-life decisions on behalf of someone else</p>	

Professional outreach, training, support and education concerning the care of those with serious chronic and life-threatening conditions

KEY FINDING: Significant variation in knowledge and practice exists within the health-care provider community related to available end-of-life and palliative care services and supports.

- ❖ **Education and training opportunities related to palliative and end-of-life care are emerging but they are largely disconnected.** Hospitals, provider organizations, educational institutions and other entities offer training but there is not a notable degree of coordination among them at present. Regarding certification, new offerings are becoming available but it is not yet clear which providers are likely to participate and whether such training will be mandated (by employers, payers or others). Education and

training are also needed for those entities responsible for addressing issues of guardianship and responsibility for health care decision making (e.g. family courts, elder law, bar association, attorneys in private practice.) The State can play a role in promoting coordination and expansion of training and educational offerings as well as tracking participation to better understand penetration rates.

- ❖ **Providers do not always understand the system of palliative and end-of-life care and therefore may not refer patients to appropriate resources and supports.** In particular, it was noted that hospice referrals often occur so close to the end of the life that the patient and family are unable to realize the full benefits of hospice. Early referrals to hospice allow the patient and family to access comfort care and an array of supports that enable a better quality of life while there is still time to enjoy it as well as access to grief and bereavement supports after the patient has died. Specific guidance and supports may promote greater provider awareness of hospice benefits and more productive clinician-patient discussions regarding end-of-life and palliative care.
- ❖ **Patient goals and preferences may conflict with those of the provider, especially relative to faith and other non-medical considerations.** Newly created and expanding palliative and end-of-life care programs present an opportunity to educate providers and consumers about the important consultative role of the health care provider. Individuals will weigh medical and non-medical considerations as they make decisions related to end-of-life and palliative care. Appropriate provider training must address cultural competencies and provider bias.
- ❖ **Frequent clinician-patient conversations about end-of-life and palliative care help clarify treatment choices among patients, clinicians and loved ones.** Understanding one's condition and available options takes time and patient goals may shift based on new information, so engaging in regular and open conversations about end-of-life and palliative care preferences can help to ensure that they are observed and enables the patient to make an informed decision in consultation with the team of care. This is especially true when other family members and decision makers are included in these conversations.

Recommendation	Responsible Party
1. Support and monitor progress toward inclusion of end-of-life and palliative care services and supports in healthcare delivery.	HCC/DEOLC/DCHI
2. Include end-of-life and palliative care issues in the DCHI's workforce learning and re-learning curriculum.	DCHI
3. Include end-of life and palliative care issues in the work of the DCHI's Graduate Health Professional Consortium.	DCHI
4. Specifically promote palliative and end-of-life care educational offerings as a means to meet continuing education requirements for providers at all levels.	Professional organizations

Enabling access to palliative care services and supporting the capacity in the health care system to provide palliative care services in home, community, hospice, skilled nursing facilities, hospital and any other relevant settings

KEY FINDING: An array of palliative care offerings is currently available in Delaware but both consumers and providers experience difficulty in understanding and accessing these services.

- ❖ **Most hospitals in Delaware have a palliative medicine program and all have signaled an interest in expanding offerings in the future.** According to the results of the Delaware Healthcare Association's Palliative Care Council survey of hospitals, palliative care offerings are present at the majority of the state's hospitals and most are tracking the provision of services. There is significant interest in increasing offerings and several hospitals indicate that information sharing and technical support may help facilitate this.
- ❖ **Patients and caregivers face many challenges and limitations in receiving/providing care outside of the hospital setting.** The end-of-life phase is often marked by multiple transitions among care settings and providers, which can pose challenges to adequately addressing patient needs and goals. Additionally, patients with serious illness may struggle to access the care and support services they need to thrive outside the hospital setting, particularly if they have challenges related transportation, mobility and sensory deficit. Family members often have inadequate support or ability to address patient needs, causing personal and financial stress. Nursing care to address needs including the administering of medication is costly and beyond the reach of many families. Wrap-around supports can help to address patient and family needs across the spectrum of care, and payers may be able to play a role in reducing acute care costs by providing reimbursement for these services.
- ❖ **Provider and patient understanding of the offerings and benefits of palliative and end-of-life care is often lacking and therefore leads to underutilization.** Additionally, patients and families may not know how to initiate the process of accessing palliative or hospice care if it is not specifically mentioned by the provider. For providers, incorporating palliative and end-of-life care offerings into the standard workflow of provider systems will help to facilitate appropriate referrals to palliative care, although it is likely to require a cultural shift among systems and providers. For patients, making information about palliative and end-of-life care available in a variety of care settings will promote greater awareness of these offerings and may prompt patient-initiated discussions about whether they are appropriate for the patient.

Recommendation	Responsible Party
1. Support and monitor the growth of palliative and end-of-life care services offered in inpatient and community-based settings. Activities should be formally aligned with the Clinical and Workforce committees of the DCHI and should include, at minimum:	DEOLC/DHA/DCHI
a. Adoption of nationally-recognized professional and program standards where available b. Creation of Delaware-specific program and professional guidance where appropriate to assure that issues of individual abilities, culture, and language are adequately addressed	
2. Facilitate coordination among Delaware’s hospitals and providers as they develop programs and resources related to palliative and end-of-life care.	DHA
3. Using resources compiled by the Delaware End-of Life Coalition as a basis, build and continue to update a compendium of resources related to end-of-life and palliative care for consumers, advocates, and service providers.	DEOLC
4. Review existing policies limiting the ability of home care service providers and family members to perform healthcare-related tasks on behalf of patients.	DEOLC
5. Explore mechanisms to make patient wishes readily accessible in a variety of settings.	DEOLC, DMOST Coalition, DHIN
6. Examine how additional funding for social services might yield positive health impacts for patients in need of additional supports in and around the home.	DEOLC
7. Develop supports to mitigate the impact on family members who leave or reduce employment to care for a loved one.	DEOLC
8. Urge continued efforts to facilitate access to mobility and sensory aids (i.e. hearing aids, glasses and power chairs).	DEOLC

Other recommendations to support comprehensive health care services to Delawareans with advanced and serious illness

KEY FINDING: Delaware-specific data related to the quality, availability and utilization of end-of-life and palliative care services is not readily available. The workgroup agreed that Delaware’s efforts to promote palliative and end-of-life care offerings would be aided by the compilation of detailed information about existing offerings in various settings. Data collected will enable identification of gaps and potential opportunities for service offerings. For each program, the workgroup suggests documenting:

- Settings in which programs are offered (hospice, home, outpatient, other)
- Nature of programs and service offerings
- Target audience (patients, caregivers, other)
- Data about numbers served/reach of programs

The PCC has begun the work of gathering this data from hospitals through its recent survey and follow-up work; similar data from outpatient providers should be gathered. It is recommended that Delaware actively engage with academic institutions in the state to determine what data, research and program offerings are available related to palliative and end-of-life care. Other Delaware resources that could support these efforts include the Behavioral Health Risk Factor Surveillance System (BRFSS) and its annual survey conducted by the Division of Public Health, which might be expanded to include questions related to palliative and end-of-life care; and the Delaware Health Information Network, which might be leveraged to provide and/or house data relative to these items. Capturing and tracking this data will facilitate more meaningful measurement of activity levels and progress related to end-of-life and palliative care issues in the future.

Recommendation	Responsible Party
1. Using existing data and data collection tools as a foundation, develop and implement a comprehensive, statewide approach to gathering and using data related to end-of-life and palliative care. The comprehensive approach should include, at minimum:	DEOLC, Academic institutions, DPH, DHIN, DCHI
a. An annual survey of the public to understand current status of and changes to knowledge, attitudes and behaviors surrounding palliative and end-of-life care for use in guiding priorities for further action	
b. Evaluation of data available through the Delaware Health Information Network (DHIN), Behavioral Risk Factor Surveillance System (BRFSS) and other available data	
c. An annual survey of health care and palliative care providers to assess current status of and changes to practice related to end-of-life and palliative care for use in evaluating effectiveness of interventions and guiding priorities	

V. Cost Estimates

This workgroup was charged with developing a set of recommendations regarding end-of-life care and related issues in Delaware with the assumption that Delaware could use these recommendations as the basis for undertaking activities that would better address patient, consumer and provider needs in this area. Hence, the recommendations were developed without significant consideration given to implementation costs but rather with the intent to envision and provide a roadmap for achieving the desired system of care and related tools and supports.

Understanding, however, that cost estimates are useful for planning purposes and setting priorities, the workgroup has developed a high level set of cost estimates for what are considered to be significant items that will likely require the outlay of additional funds for implementation. These items are further described in the Section IV of this report.

Item	Estimated Cost	Description
DE End-of-Life Coalition and/or Health Care Commission transitional and ongoing operational costs	\$250,000 in year one; \$150,000 annually thereafter	<ul style="list-style-type: none"> • Hiring of a full-time program manager at the DEOLC to manage those initiatives within the group’s purview under a new operating model • Costs associated with the transition of ownership to the DEOLC that may include the drafting of bylaws, attorney fees and other ancillary costs • Hiring of an advisor with specific subject matter expertise to advise Delaware during the transition and ramp-up period
Statewide awareness campaign	\$700,000	Implementation of a multi-platform campaign across Delaware to promote awareness and understanding of issues and resources related to end-of-life and palliative care

These cost estimates are a starting point for discussion and may fluctuate based on Delaware’s preferences regarding the nature and scope of activities, which may be further explored during the transitional period. It is anticipated that these costs will be addressed through a combination of new and existing resources across the public and private sectors.

APPENDICES

Appendix A. Workgroup Membership and Contributors

The End-of-Life Workgroup would like to thank all of those who contributed to the dialogue around end-of-life and palliative care issues in Delaware over the past few months. Below is a listing of the workgroup members and their affiliations, followed by a full listing of those individuals that attended a workgroup meeting or public listening session and/or provided written comments related to the final report and other workgroup efforts.

Workgroup Members

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Appendix B. Glossary of Terms

Several of the below definitions were taken or adapted from other sources for inclusion in this report. In those instances, the source of the definition is indicated.

Advance Care Planning: Advance care planning is an ongoing process of discussing and clarifying the current state of a person's goals, values and preferences for future medical care.¹³

Advance Health Care Directive: an individual instruction or power of attorney for health care, or both.¹⁴ Advance directive is a general term referring to a written document to direct future medical care in the event that a person loses capacity to make health care decisions (i.e., becomes incapacitated). It sometimes results from the process known as advance care planning. A health care proxy or a living will is considered to be an advance directive.¹³

Behavioral Risk Factor Surveillance System (BRFSS): A unique, state-based surveillance system geared toward providing health agencies with information about public behavioral health risks in order to plan, implement and evaluate health education and disease prevention programs for the public. In Delaware, the Behavioral Risk Factor Survey (BRFS) is a random-sample telephone interview survey conducted by the Division of Public Health every month of every year with data analyzed on a calendar-year basis.

Capacity: means a patient's ability to understand and appreciate the nature and consequences of a particular health-care decision, including the benefits and risks of that decision and alternatives to any proposed health care, and to reach an informed health-care decision.¹⁴ Capacity can vary over time, and illness or medication can affect the person's capacity. If you are unsure whether a person has capacity to make health care decisions, you can ask a doctor or clinician to make a medical determination.¹³

Cardiopulmonary Resuscitation (CPR): a set of medical procedures that attempt to restart the heartbeat and breathing of a person who has no heartbeat and has stopped breathing. Such procedures may include the following:

- Pressing on the chest to mimic the heart's functions and cause blood to circulate
- Inserting an airway into the mouth and throat, or inserting a tube into the windpipe
- Ventilating artificially, through mouth-to-mouth or other mechanically assisted breathing
- Using drugs and/or electric shock (defibrillation) to stimulate the heart

CPR can be life-saving in certain cases for otherwise healthy people may not be as effective when a person has a serious chronic illness.¹³

Delaware Center for Health Innovation (DCHI): a non-profit organization established in 2014 to work with the Health Care Commission and the Delaware Health Information Network (DHIN) to guide the State Innovation Model effort and track its progress. DCHI is a public-

¹³ "Terms and Definitions." Honoring Choices Massachusetts.

<http://www.honoringchoicesmass.com/resources/glossary/#sthash.NnsoHaQe.dpuf>

¹⁴ Delaware Code. Title 16, Chapter 25A. *Delaware Medical Orders for Scope of Treatment Act*. Section 2503A: Definitions. <http://delcode.delaware.gov/title16/c025a/index.shtml>

private partnership focused on achieving the triple aim of improving population health, improving care, and reducing healthcare costs.

Delaware End-of-Life Coalition (DEOLC): a 501 (c)(3) organization begun in 2000 that provides educational programs for both professional and public audiences and promotes dialogue about end-of-life issues throughout the state of Delaware. DEOLC membership is composed of nurses, physicians, social workers, hospice staff, clergy, educators, grief counselors, funeral home staff and many others.

Delaware Health Care Commission (HCC): The Delaware General Assembly created the Delaware Health Care Commission in June of 1990 to develop a pathway to basic, affordable health care for all Delawareans. A public/private effort with representation from four government officials and six private citizens, the HCC is a policy-setting body expressly authorized to conduct pilot projects to test methods for catalyzing private-sector activities that will help the state meet its health care needs and has oversight over several State initiatives working toward that end.

Delaware Healthcare Association (DHA): a statewide trade and membership services organization that exists to represent and serve hospitals, health systems, and related health care organizations in their role of providing a continuum of appropriate, cost-effective, quality care to improve the health of the people of Delaware. The primary role of the Association is to serve as a leader in the promotion of effective change in health services through collaboration and consensus building on health care issues at the State and Federal levels.

Delaware Health Information Network (DHIN): The Delaware Health Information Network (DHIN) was established by the Delaware General Assembly in 1997 to advance the creation of a statewide health information network and to address Delaware's needs for timely, reliable and relevant health care information. DHIN went live in May 2007, becoming the first operational statewide health information exchange in the country and has since expanded the types and sources of clinical information available to meet the needs of Delaware's health care community, now delivering more than 7 million clinical results and reports each year to nearly 400 practices and health care organizations around the state.

Delaware Medical Orders for Scope of Treatment (DMOST): a program designed to improve the quality of care Delaware residents receive at the end of life by translating patient/resident goals and preferences into medical orders. The full text of the recently passed DMOST legislation may be found at:

[http://legis.delaware.gov/LIS/lis148.nsf/vwLegislation/HB+64/\\$file/legis.html?open](http://legis.delaware.gov/LIS/lis148.nsf/vwLegislation/HB+64/$file/legis.html?open)

DNR (Do Not Resuscitate) orders: medical orders, signed by a physician, nurse practitioner, or physician's assistant that instruct health care providers not to attempt cardiopulmonary resuscitation (CPR) in the event of cardiac and respiratory arrest.¹³

End of Life Care (A Working Definition): care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life

and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.²

End-of-Life Decisions: decisions that require a range of questions including palliative care, patients' right to self-determination, medical experimentation, and ethics. These decisions don't refer only to patients in the final hours or days of their lives, but more broadly care of all those with a terminal illness or terminal disease condition that has become advanced, progressive and incurable. Ideally, end-of-life decisions respect the person's values and wishes while maintaining his or her comfort and dignity.

Guardian: a judicially appointed guardian or conservator having authority to make health care decisions for an individual.

Health Care: any care, treatment, service or procedure to maintain, diagnose or otherwise affect an individual's physical or mental condition.

Health Care Decision: a decision made by an individual or the individual's agent, surrogate or guardian regarding the individual's health care, including:

1. Selection and discharge of health care providers and institutions;
2. Acceptance or refusal of diagnostic tests, surgical procedures, programs of medication resuscitation; and
3. Directions to provide, withhold or withdraw artificial nutrition and hydration and all other forms of health care.

Health Care Provider: a person, corporation, facility or institution licensed to provide health care or professional services.

Hospice: Considered to be the model of quality, compassionate care for people facing life-limiting illness or injury, hospice care involves a team-oriented approach to medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is provided to the patient's loved ones as well. At the center of hospice and palliative care is the belief that each person has the right to die pain-free and with dignity, and that families will receive the necessary support to allow this to occur. Hospice also provides bereavement support after death occurs.³

Life-sustaining Procedure/Treatment: 1. Any medical procedure, treatment or intervention that: a. Utilizes mechanical or other artificial means to sustain, restore, or supplant a spontaneous vital function; and b. Is of such a nature as to afford an individual no reasonable expectation of recovery from a terminal condition or permanent unconsciousness. 2. Procedures that can include, but are not limited to, assisted ventilation, renal dialysis, surgical procedures, blood transfusions and the administration of drugs, antibiotics and artificial nutrition and hydration.

Living Will: a personal document or statement in which a person specifies future medical treatments in the event of incapacity, usually at end of life or if one becomes permanently unconscious, in a persistent vegetative state or "beyond reasonable hope of recovery."¹³

Medically Ineffective Treatment: means that, to a reasonable degree of medical certainty, a medical procedure will not:

1. Prevent or reduce the deterioration of the health of an individual: or
2. Prevent the impending death of an individual.

Palliative medicine (or care) is specialized medical care for people with serious illnesses. It focuses on providing relief from the pain, symptoms and distress of serious illness. It is a team-based approach to care involving specialty-trained doctors, nurses, social workers and other specialists focused on improving quality of life. By determining patients' goals of care through skilled communication, treating distressing symptoms and coordinating care, palliative care teams meet patients' needs and help them avoid unwanted and expensive crisis care. Unlike hospice care, palliative care can be provided *at the same time* as curative treatments; it is appropriate at any age and at any stage of a serious illness.¹ Palliative care is focused on improving quality of life and does not intend to either prolong living beyond what is natural or hasten death.

Person-centered care (or patient-centered care): Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.

Physician: an individual licensed to practice medicine. In Delaware, physician licensing is governed by Chapter 17 of Title 24 of the Delaware Code.

Physician Aid in Dying: refers to a practice in which a physician provides a competent, terminally ill patient with a prescription for a lethal dose of medication, upon the patient's request, which the patient intends to use to end his or her own life. This may also be referred to as physician-assisted death or physician-assisted suicide.

Power Of Attorney For Health Care: the designation of an agent to make health care decisions for the individual granting the power.

Primary Physician or Attending Physician: a physician designated by an individual or the individual's agent, surrogate or guardian to have primary responsibility for the individual's health care or, in the absence of a designation, or if the designated physician is not reasonably available, a physician who undertakes the responsibility for the individual's health care.

Serious illness (or health condition): an illness, injury, impairment, or physical or mental condition that involves: inpatient care in a hospital, hospice, or residential medical care facility; or continuing treatment by a health care provider. Serious illnesses include cancer, heart disease, kidney disease and dementia, among others.

State Innovation Model (SIM): a national grant program administered by the Center for Medicare & Medicaid Innovation (CMMI) with the goal of supporting states to move toward value-based payment models and to improve population health. Delaware has received grant funding through SIM to develop and implement a State Health Care Innovation Plan to improve the health of Delawareans, improve health care quality and patient experience, and control the

growth in health care costs. Implementation of the SIM initiative is being led by the Delaware Center for Health Innovation.

Supervising Health Care Provider or Health Care Provider: the primary physician, or if there is no primary physician or the primary physician is not reasonably available, the health care provider who has undertaken primary responsibility for an individual's health care.

Terminal Condition: any disease, illness or condition sustained by any human being for which there is no reasonable medical expectation of recovery and which, as a medical probability will result in the death of such human being regardless of the use or discontinuance of medical treatment implemented for the purpose of sustaining life or the life processes.

Appendix C. Annotated Bibliography of Resources

For those wishing to further explore topics related to this report, below is a list of recommended resources with a brief explanation of content.

Institute of Medicine (2014). *Dying in America, Improving Quality and Honoring Individual Preferences Near the End of Life.*

<http://iom.nationalacademies.org/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx>

A substantial body of evidence shows that broad improvements to end-of-life care are within reach. In *Dying in America*, a consensus report from the Institute of Medicine (IOM), a committee of experts finds that improving the quality and availability of medical and social services for patients and their families could not only enhance quality of life through the end of life, but may also contribute to a more sustainable care system.

The National Academy of Medicine and ReachMD (2016). Podcast series based on *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life.*

https://www.reachmd.com/programs/dying-in-america-series/?utm_source=Radio_Promo&utm_medium=Radio&utm_campaign=Dying_in_America_Radio_Promo_2016

Providing high-quality end-of-life care is a major commitment and responsibility faced by millions of health care professionals every day. In this new podcast series for health care professionals based on the 2015 Institute of Medicine report, hear about various aspects of end-of-life care from the perspective of experts in the field. Topics include palliative care, interdisciplinary teamwork, clinician-patient communication and advance care planning, and policies and payment systems for care near the end of life.

United Health Foundation (2015). *America's Health Rankings Senior Report, A Call to Action for Individuals and Their Communities.* <http://www.americashealthrankings.org/senior>

This report helps states prepare for rapid growth of their senior population. Today, 1 in 7 Americans are aged 65 and older, and in 35 years this age group is projected to double to 83.7 million. This surge and the increasing rates of obesity, diabetes, and other chronic diseases are poised to overwhelm our health care system. The United Health Foundation developed this report to provide a benchmark for gauging how a state's senior health changes and compares with that of other states and the nation.

Center to Advance Palliative Care, National Palliative Care Research Center (2015). *America's Care of Serious Illness, 2015 State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals.* <https://reportcard.capc.org/>

The *State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals* provides an analysis of whether seriously ill patients in the United States are receiving equitable access to palliative care services in hospitals. The goal is both to inform and to help the public and policymakers increase the availability of palliative care for the millions of Americans in need.

National Institute on Aging, National Institutes of Health (2012). End of Life, Helping with Comfort and Care. <https://www.nia.nih.gov/health/publication/end-life-helping-comfort-and-care/introduction>

End of Life: Helping With Comfort and Care hopes to make the unfamiliar territory of death slightly more comfortable for everyone involved. This publication is based on research such as that supported by the National Institute on Aging, part of the National Institutes of Health. This research base is augmented with suggestions from practitioners with expertise in helping individuals and families through this difficult time. *Helping With Comfort and Care* provides an overview of issues commonly facing people caring for someone nearing the end of life. It can help readers work with health care providers to complement their medical and caregiving efforts.

Center to Advance Palliative Care (2011). Public Opinion Research on Palliative Care. https://media.capc.org/file_public/3c/96/3c96a114-0c15-42da-a07f-11893cca7bf7/2011-public-opinion-research-on-palliative-care_237.pdf

This research was supported by the American Cancer Society and the American Cancer Action Network. The recommendations built into this report provide a roadmap for communicating with consumers and policymakers on the benefits and future direction of palliative care. This report provides an in-depth look at appropriate messages, as well as attitudes and perceptions of palliative care.

DMOST Legislation – Delaware House of Representatives 148th General Assembly, Bill No. 64

[http://legis.delaware.gov/LIS/lis148.nsf/vwLegislation/HB+64/\\$file/legis.html?open](http://legis.delaware.gov/LIS/lis148.nsf/vwLegislation/HB+64/$file/legis.html?open)

Text of the DE Legislative bill passed in May 2015 regarding the Delaware Medical Orders for Scope of Treatment (DMOST) program, which is designed to improve the quality of care people receive at the end of life by translating patient/resident goals and preferences into medical orders. DMOST is intended to provide a single document that will function as an actionable medical order and could transition with a patient through all health care settings. It is intended that the form will be transported with the patient between different health care settings in order that their wishes for life-sustaining treatment and CPR will be clearly indicated.

Center to Advance Palliative Care (2014). Implications of a new Institute of Medicine report: Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life

This slide deck analyzes the five main recommendations contained within the IOM's report on Dying in America. The five recommendations include a focus on person-centered and family-oriented care, the importance of clinician-patient communication and advance care planning, professional education and development, policies and payment systems, and public education and engagement. The Center to Advance Palliative Care looks to leverage these recommendations to strengthen access to quality palliative care and provides their own set of five recommendations.

The Journal of the American Medical Association (2015). The Next Era of Palliative Care

http://jama.jamanetwork.com/article.aspx?articleid=2436391&utm_campaign=articlePDF&utm_medium=articlePDFlink&utm_source=articlePDF&utm_content=jama.2015.11217

This is an opinion piece from two medical doctors at the Division of General Internal Medicine, Section of Palliative Care and Medical Ethics. One of the main takeaways is that the next era of palliative care must embrace a broader focus on systems of care, measurement and accountability for palliative services, and national policy changes that promote universal provision of high-quality advanced illness care. The authors also identify three changes that need to occur in order to improve palliative care for patients with serious illnesses. First, palliative care specialists need to develop skills in clinician behavior change, system change, and quality improvement. Second, health systems need to expand their focus to develop programs that measure and improve the quality of palliative care that every patient receives. Third, federal funding must be aligned with a national goal of improving the experience of seriously ill patients and their loved ones.

The New England Journal of Medicine (2015). Palliative Care for the Seriously Ill.

<http://www.nejm.org/doi/full/10.1056/NEJMra1404684>

This NEJM article addresses the differences between palliative care and hospice care, provides recommendations from the National Consensus Project for Quality Palliative Care, identifies the frequency of certain symptoms in advanced illness and discusses the main models of palliative care. These models of care include hospital-based, community-based, and long term care. A discussion on expanding access to palliative care and barriers to care is included, as well as an identification of the evidence gaps and the future direction of palliative care.

California Health Care Foundation, Coalition for Compassionate Care of California (2015). Dying in California: A Status Report on End-of-Life Care

<http://coalitionccc.org/2015/10/report-california-making-progress-toward-a-supportive-environment-for-end-of-life-care/>

This report identifies the five key recommendations included in the IOM's Dying in America report and discusses California's progress, as well as gaps and opportunities, for each recommendation. The report looks ahead to the status of end-of-life care in California and recognizes that California still has a long way to go in order to improve. Thoughtful, compassionate end-of-life care is one of the key goals of Let's Get Healthy California, the statewide effort to make California the healthiest state by 2022.

Gundersen Health System. Transforming Healthcare: Advance Care Planning

<http://www.gundersenhealth.org/upload/docs/respecting-choices/6035-4 Transforming%20Healthcare RC web.pdf>

Gundersen Health System is leading the nation with an innovative program that is designed to help healthcare providers and the patient's caregivers understand and honor a patient's preferences for future medical treatment. Their system increases continuity of care, quality of life and respect for the patient's wishes, while matching health services to patient preferences and

reducing utilization of unwanted medical treatments. This report outlines Gunderson's model of care for patients with advanced illness, with two three main components: a community approach, availability of information as a standard practice, and professional education.

Center to Advance Palliative Care, National Palliative Care Research Center (2015). The Status of Palliative Care in the United States: An Update

This is an update to the 2015 CAPC State Report Card and addresses the following:

- Who are the high risk high cost patients?
- The needs of the seriously ill and their families
- Why palliative care is the solution
- How is our nation doing?

This report shows that palliative care has grown dramatically in U.S. hospitals as it has grown from 15% in 1998 to 67% in 2014. The path forward for the next five years includes an effort to support southern, smaller, and for-profit hospitals to develop palliative care programs.

Former Sen. Bill Frist (R-TN) My Directives. Digitize your own advanced-care plan

<http://thehill.com/opinion/op-ed/193444-digitize-your-own-advanced-care-plan>

This is an op-ed from former Senator Bill Frist encouraging readers to use MyDirectives.com to help family members and friends navigate end-of-life care. MyDirectives.com, for instance, offers free digital advance medical directive forms online with instructions on completion and how to introduce the subject with family. The service helps ensure doctors can find an individual's directive online during a crisis.

British Medical Journal (2010). The impact of advance care planning on end of life care in elderly patients: randomized controlled trial

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2844949/>

The objective of the trial was to investigate the impact of advance care planning on end of life care in elderly patients. Participants were randomized to receive usual care or usual care plus facilitated advance care planning. Advance care planning aimed to assist patients to reflect on their goals, values, and beliefs; to consider future medical treatment preferences; to appoint a surrogate; and to document their wishes. 154 of the 309 patients were randomized to advance care planning, 125 (81%) received advance care planning, and 108 (84%) expressed wishes or appointed a surrogate, or both. Of the 56 patients who died by six months, end of life wishes were much more likely to be known and followed in the intervention group (25/29, 86%) compared with the control group. The main conclusion is that Advance care planning improves end of life care and patient and family satisfaction and reduces stress, anxiety, and depression in surviving relatives.

Coalition to Transform Advanced Care <http://www.thectac.org/key-initiatives/policy-advocacy/>

The Coalition to Transform Advanced Care (C-TAC) is dedicated to the ideal that all Americans with advanced illness, especially the sickest and most vulnerable, receive comprehensive, high-

quality, person- and family-centered care that is consistent with their goals and values and honors their dignity. The Coalition aims to achieve this by empowering consumers, changing the health delivery system, improving public and private policies, and enhancing provider capacity.

Atul Gawande, Being Mortal <http://atulgawande.com/book/being-mortal/>

Atul Gawande, a practicing surgeon, examines his profession's ultimate limitations and failures – in his own practices as well as others' – as life draws to a close. And he discovers how we can do better. He follows a hospice nurse on her rounds, a geriatrician in his clinic, and reformers turning nursing homes upside down. He finds people who show us how to have the hard conversations and how to ensure we never sacrifice what people really care about.

The American Academy of Pediatrics - Pediatric Palliative Care and Hospice Care Commitments, Guidelines, and Recommendations.

<http://pediatrics.aappublications.org/content/132/5/966>

In this report the American Academy of Pediatrics outline the core commitments that serve as the foundation for an integrated model of Pediatric Palliative Care and Pediatric Hospice Care (PPC-PHC). The report goes on to propose guidelines and recommendations based on a combination of published observational studies, expert opinion, and consensus statements.

American Academy of Pediatrics (2012). Supporting the Family After the Death of a Child.

<http://pediatrics.aappublications.org/content/130/6/1164.long>

The death of a child can have a devastating effect on the family. The pediatrician has an important role to play in supporting the parents and any siblings still in his or her practice after such a death. Pediatricians may be poorly prepared to provide this support. Also, because of the pain of confronting the grief of family members, they may be reluctant to become involved. This statement gives guidelines to help the pediatrician provide such support. It describes the grief reactions that can be expected in family members after the death of a child. Ways of supporting family members are suggested, and other helpful resources in the community are described. The goal of this guidance is to prevent outcomes that may impair the health and development of affected parents and children.

American Academy of Pediatrics Committee on Pediatric Emergency Medicine (2014).

Death of a Child in the Emergency Department. <http://www.jenonline.org/article/S0099-1767%2814%2900203-7/abstract>

The American Academy of Pediatrics, American College of Emergency Physicians, and Emergency Nurses Association have collaborated to identify practices and principles to guide the care of children, families, and staff in the challenging and uncommon event of the death of a child in the emergency department in this policy statement and in an accompanying technical report.

National Hospice and Palliative Care Organization (NHPCO) Website

<http://www.nhpc.org/pediatric>

NHPCO is the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. The organization is committed to improving end of life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people dying in America and their loved ones. NHPCO also published a toolkit titled “Concurrent Care for Children Implementation Toolkit”.

http://www.nhpc.org/sites/default/files/public/ChiPPS/CCCR_Toolkit.pdf

Aging with Dignity Website <https://agingwithdignity.org/>

Aging with Dignity, with the help of national experts, has developed guides for children and adolescents, who have needs that are not necessarily met in a standard advance directive. [My Wishes](#), for pediatric patients, and [Voicing My Choices](#), for adolescents, use developmentally appropriate language, medical terms, and themes. Both documents are the nation’s first tools that allow youth living with life-limiting illness to express and share their preferences for how they wish to be cared for and remembered.

Courageous Parents Network Website <http://courageousparentsnetwork.org/>

Courageous Parents Network empowers and supports parents caring for children with life-threatening illness by using Web and Mobile to: (1) provide parents with coping tools to promote resiliency ; (2) bring parents into 24/7 community with each other to lessen isolation; (3) educate medical providers about the psycho-social and emotional needs of these families; (4) promote pediatric palliative care. The vision is that the family’s journey is one of minimal regret and maximum healing.

Appendix D. Public Listening Session Key Themes and Considerations

The workgroup benefitted from robust attendance at statewide listening sessions and participant willingness to share thoughts, perspectives, resources and personal experiences related to palliative and end-of-life care. This document seeks to capture the predominant themes and related comments shared during the sessions, grouped according to major focus areas and other topics.

Consumer outreach, awareness and education activities regarding palliative and end-of-life care and planning, including advanced care planning and the recently enacted DMOST legislation

- Clarification is needed on the difference between advance care directives/living wills/Delaware Medical Orders for Scope of Treatment (DMOST).
 - DMOST is a medical order that can only be completed in the expected last year of a patient's life and allows patients to ask for the most or least amount of care they would like to receive.
 - Advance care directives are legal documents and can be completed at any time.
 - Participants suggested there is no template or form available to them that explains the medical order/advance directive process and guides them to have conversations with their family and friends.
 - Advance care directives may pose challenges because of inconsistencies and no clear conflict-of-interest clauses.
- Include Family and Friends in Advance Directive Planning Process
 - More times than not patients do not think about an advance directive before it is too late and a crisis forces them to consider the issue.
 - End-of-life discussions are applicable to all – not just the old and sick.
 - Family members and friends need to be involved in any discussions or plans around advance directives. Too many times a patient develops an advance directive without consulting family members and friends, who can be caught off guard in the hospital when the medical team executes the patient's wishes.
 - Family members and loved ones are often left feeling guilty and questioning whether they made the right decisions for the patient.
 - When people are sick and estranged from family, getting financial information is often difficult. Going through the guardianship process is an option but often takes several weeks.
 - Children or other loved ones may disagree about a family member's care, so designating Power of Attorney or a proxy is important.
- Each individual has a right and a responsibility to determine his or her wishes related to end-of-life and palliative care.
 - A number of participants relayed experiences where they could tell that their loved ones did not want the extensive end-of-life care they were receiving. They felt powerless and wished they had completed an advance directive or been even more specific in the advance directive they did complete.
 - "Major fear is that I won't be able to die when I want to."

- People with different backgrounds and faiths may have different priorities.
- Families need education about what it means to be a surrogate and making decisions – this is difficult to do even with direction.
- People are frightened about having to sign off on something.
- The patient’s primary preference may be comfort, even while undergoing aggressive treatment. It is important to emphasize that palliative care can be whatever you wish.
- Executing patient preferences may be complicated when one is on suicide watch or depressed.
- In some cases life prolonging capabilities may cause harm. How much do we want providers to do to keep us alive?
- Believe that in most cases patients make the right decisions and the system works as designed.

Best Practices

- La Crosse, Wisconsin: over 90% of residents have completed an advance directive. La Crosse, Wisconsin spends less on health care for patients at the end of life than any other place in the country, according to the Dartmouth Health Atlas.
- Money Follows the Person cited as a successful model.
- Consider holding public clinics and asking lawyers to volunteer so the service is free.
- Make consumers aware of Delaware and national resources such as Five Wishes: a legal document that lets everyone plan for how they would like to be treated during end-of-life care. This form can be picked up at any of Delaware’s six hospices and will be honored in all Delaware hospitals.
- Move to value based and person centered care in some cases is enabling for longer interactions between patient and provider and thus more time for important discussions such as these.
- It is important that someone take the lead on these issues and craft a campaign around community awareness leveraging community centers, senior centers and other resources.

Leverage Existing Resources

- Conduct outreach to the religious community to reach a broader group of Delawareans. These organizations are often brought into these conversations by families and others and many have developed resources related to end-of-life care.
- Other potential community outreach partners: senior centers, Federally Qualified Health Centers, community centers, Meals on Wheels, Sunday Breakfast Mission, Coffee with Constituents, Greater Lewes Community Village.
- National resources: Five Wishes, The Conversation Project, Death Over Dinner, National Healthcare Decisions Day (April 16)
- Potential opportunity to leverage the workforce training systems and measures that were established as part of the Affordable Care Act implementation. Examples include Marketplace Guides, Navigators, etc.
- Look back at successful programs in Delaware and take appropriate lessons learned. Examples include:
 - Tobacco Prevention

- Colonoscopy 50th birthday card
- Get millennials to talk about this – have students develop something and give them credit for completing it.

Professional outreach, training, support and education concerning the care of those with serious chronic and life-threatening conditions

Education and Training for Providers

- Providers need to be educated as well as patients. A number of participants claimed from experience that they interacted with doctors who did not understand the exact requirements/eligibility for hospice care, palliative care, etc. Providers should encourage families to talk with social workers and others who can help.
- Social workers were cited as another resource who could be trained on end-of-life care issues with providers as they interact with end-of-life patients on a regular basis.
- Some patients will want the most extensive coverage possible, while others will want the bare minimum. It is up to the medical team to respect and honor those wishes.
- Some participants claimed the only way to effectively train a large number of providers is to mandate end-of-life and palliative care training.
- Consider offering listening sessions for providers – what information do they need?
- Cultural competency, including around care of people with disabilities, is needed. Providers may think they know better than the patient regarding needs.
- Providers other than primary care physicians can be brought into the end-of-life conversations with patients. Examples include nurses and social workers. These individuals could informally talk to patients about their recent diagnosis and ask them what their plan is for the future.

Importance of Provider/Patient Communication

- Providers need to be included in the advance directive planning conversation with patients especially since they may not be available if and when a patient is admitted to the hospital under an end-of-life diagnosis. In that case, providers are left to interpret what's written as best as they can under the circumstances, which may not match the patient's wishes.
- Many participants noted that a doctor does not always know what is best for the patient. It is important for providers to understand patient concerns and for patients to advocate for themselves.
- As Delaware looks to move to a more value-based payment model, physicians are now able to code their time to have substantive conversations with their patients on planning for end-of-life and palliative care.
- New Medicare rules allow for an initial advance planning conversation between doctor and patient that can last as long as 30 minutes.

Other

- Participants questioned the legal ramifications of providers and/or hospitals not honoring a patient's wishes.

Enabling access to palliative care services and supporting the capacity in the health care system to provide palliative care services in home, community, hospice, skilled nursing facilities, hospital and any other relevant settings

Home Care and Other Supports Outside the Hospital

- Some patients are removed from the hospital before they are ready, and before their family members are ready. There are a number of support systems that need to be in place outside of the hospital walls in order for a patient to feel safe and comfortable back in their home. This is also a burden on family members who need to put their lives on hold to care for their loved one.
- There needs to be coordination between the medical team and patient after the patient is back in the home.
- Delaware does not offer 24/7 care in the home setting and most families can't afford to pay for additional nursing care, especially when someone is out of work.
- Some states are using telemedicine to address the gap in palliative care between hospital and home care.
- An example of a resource that can be used once a patient is released from the hospital is nurses, whether they be private duty nurses, CNAs, visiting nurses, etc. Participants acknowledged these services are helpful, but not exactly affordable. Some families do not have the resources available to bring these services into the home to take after their loved ones who require around-the-clock care.
- Aides provide a more affordable home care option but may not be able to provide patients with necessary medications.
- There should be an effort to develop a workforce that can provide these services at a reasonable price.
- The cost of home health care services is an even bigger problem in Sussex County.

Other

- Hospice plays a critical role in providing comfort care to patients and support to families. Many participants described receiving wonderful care from hospice providers.
- Participants noted it would be helpful to have a health care advocate resource guide to help guide families and friends through the end-of-life care process.
- Participants discussed a recent Medicare pilot that is coming that will allow concurrent hospice and curative treatment care. The pilot will examine the financial impact of the increased levels of care.
- It would be great if Delaware could be known for providing the highest quality, compassionate care to seriously and terminally ill patients.

Other recommendations to support comprehensive health care services to Delawareans suffering from advanced and serious illnesses

- Ensure that hospital services for patients with disabilities (e.g. wheelchair bound) are sufficient to meet needs.
- Patients relying on long-term Medicaid services can wait 3-6 months before their benefits arrive. Many times it is too late for the benefits to make a difference.

- Participants noted that end-of-life patients often feel as though they are “not quite poor enough” or “not quite sick enough.” If they are just above the Medicaid threshold they find themselves stuck in a gap – coverage levels drop off at this point.
- A handful of participants noted some treatments for Medicare beneficiaries are discouraged due to the cost. Money makes its way into the decision making and care treatment processes. Participants were concerned they might not receive the proper level of care as a result.
- Delaware should definitely seek to expand palliative care services with an eye toward quality of life for patients.

Other Items

- Recommendations should consider the particular concerns of those with lower income.
- Palliative care should be available indiscriminate of financial needs. The amount of stress surrounding financial decisions exacerbates an already difficult issue.
- Patients and family members often pay a fortune for round-the-clock care. Cost must be examined, especially relative to those with no family.
- There are ways to look at cost realistically to help people with choices, e.g. saving on unnecessary ER visits.
- Concern about public policy being dictated by potential for cost savings.
- Participants expressed concern about a ‘slippery slope’ in discussing end-of-life issues in that it may lead to consideration of physician-assisted death.
- Concerns were expressed about withholding of nutrition and water being used to hasten patient death and how to ensure that physician bias does not impact decisions.
- Patient and doctor may not agree about when the end of life is.
- Life is precious and we need to be careful when dealing with it.
- Medical cannabis can play a role in improving quality of life for seriously ill patients.
- Some participants suggested that the State should not be involved in end-of-life decisions and should let the system work on its own.