

**Delaware End-of-Life Workgroup**

**FINAL REPORT AND  
RECOMMENDATIONS**

First Draft  
February 2016

Preliminary Working Document –  
Subject to Change

## I. 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 DMOST legislation and associated regulations, other relevant federal and state statutes and regulations, work and resources of Delaware End-of-Life Coalition, CMMI 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 advanced 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 relative to the above specified areas. A full list of the end-of-life workgroup membership is included as Appendix A.

An important note about this workgroup: Issues related to physician aid in dying were not included in the group's charge. While workgroup members heard impassioned perspectives on

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

## II. Table of Recommendations

Below is a high level view of the recommendations of the End-of-Life Workgroup. Additional detail related to the recommendations and associated findings are contained in Section V of this report.

<b>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</b>		
<b>Recommendation</b>	<b>Responsible Party</b>	<b>Timeframe</b>
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:	HCC/End-of-Life Coalition/DCHI	
<ul style="list-style-type: none"> <li>Standardized educational materials about palliative and end-of-life care disseminated through multiple channels</li> </ul>		
<ul style="list-style-type: none"> <li>Formal encouragement and support to civic 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</li> </ul>		
<ul style="list-style-type: none"> <li>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, culturally sensitive</li> </ul>		
<ul style="list-style-type: none"> <li>Use of new and existing tools, forms and mobile applications</li> </ul>		
<ul style="list-style-type: none"> <li>Emphasis on the role of palliative care in improving quality of life for those who are seriously and/or terminally ill</li> </ul>		
<ul style="list-style-type: none"> <li>Specific support and resources for those who may have responsibility for carrying out end-of-life decisions on behalf of someone else</li> </ul>		

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

Recommendation	Responsible Party	Timeframe
1. Support and monitor progress toward inclusion of end-of-life and palliative services and supports in the care planning process	HCC/End-of-Life Coalition/DCHI	
2. Include end-of-life and palliative care issues in the DCHI's workforce learning and relearning curriculum		
3. Include end-of-life and palliative care issues in the work of the DCHI's Graduate Health Professional Consortium		
4. Specifically promote palliative and end-of-life care education 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

Recommendation	Responsible Party	Timeframe
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:		
<ul style="list-style-type: none"> <li>Adoption of nationally-recognized professional and program standards where available</li> <li>Creation of Delaware-specific program and professional guidance where appropriate to assure that issues of individual abilities, culture, and language are adequately addressed</li> </ul>		
<ul style="list-style-type: none"> <li>Mechanisms to facilitate coordination across Delaware's health care provider communities as they develop programs and resources related to palliative and end-of-life care</li> </ul>		
2. 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		

3. Review existing policies prohibiting home care service providers from administering medication to patients		
4. Explore mechanisms to make patient wishes readily accessible in a variety of settings		
5. Examine how additional funding for social services might yield positive health impacts for patients in need of additional supports in and around the home		
6. Develop supports to mitigate the impact on family members who leave or reduce employment to care for a loved one		

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

Recommendation	Responsible Party	Timeframe
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:		
<ul style="list-style-type: none"> <li>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</li> </ul>		
<ul style="list-style-type: none"> <li>Evaluation of data available through the Delaware Health Information Network (DHIN), Behavioral Risk Factor Surveillance System (BRFSS) and other relevant data sources</li> </ul>		
<ul style="list-style-type: none"> <li>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</li> </ul>		

### Make recommendations regarding the most appropriate governance structure for ongoing support and consideration of end-of-life issues in Delaware.

Recommendation	Responsible Party	Timeframe
1. Formally link current activities related to end-of-life and palliative care with ongoing health system transformation including, at minimum:		

<ul style="list-style-type: none"> <li>• the Advance Care Planning working group of the Delaware Healthcare Association (DHCA)</li> <li>• the Delaware End-of-Life Coalition</li> <li>• the Delaware Health Care Commission</li> <li>• the Delaware Center for Health Innovation</li> </ul>		
<p>2. Primary responsibility for implementation and monitoring of the recommendations contained in this report should lie with the HCC until formal linkages are in place as outlined above.</p>		

### III. Background

The decision of the Health Care Commission (HCC) to convene a workgroup specifically focused on end-of-life and palliative care at this point in time reflects a number of factors including a growing willingness to discuss issues related to death, dying and dealing with chronic illness as well as a recognition of the need for public engagement to best address concerns related to these issues. In Delaware and nationally, efforts are underway to engage consumers, providers and others in meaningful conversations related to personal goals and preferences when it comes to receiving health care, especially when quality of life considerations are called into question.

#### Increasing 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 consumers 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.

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 certainly reflects a shift toward a person-centered approach to healthcare decisions.

### Aging population and increased prevalence of people living longer with chronic 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 to 78.8 years, the longest ever recorded.<sup>1</sup> 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.<sup>2</sup> 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 chronic 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.<sup>3</sup>

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.

### National initiatives regarding end-of-life discussions

In the past several years, many initiatives related to end-of-life planning have surfaced and a few high profile examples have come to be viewed as particularly effective models worthy of replicating or incorporating elsewhere. 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

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<sup>1</sup>"CDC: Life Expectancy in the US Reaches Record High." *Medical News Today*. October 8, 2014. <http://www.medicalnewstoday.com/articles/283625.php>

<sup>2</sup>"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>

<sup>3</sup>"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>

have an advance care directive. Nationally, estimates vary as to how many individuals have completed advance directives but the number is thought to be 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. The success of and interest in these initiatives also underscores the importance of Delaware opting to further explore these issues at this time.

### Other developments in Delaware and nationally

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, 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.
- **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.
- **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, Delaware passed this legislation creating a set of portable end-of-life medical orders designed to improve the quality of care people receive at the end of life. The intended user of the DMOST form is a patient whose continued life expectancy is less than one year and the form must be completed by the patient in concert with his or her physician.
- **Palliative Care Council:** The Delaware Healthcare Association's Palliative Care Council 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 defining standards and metrics for inpatient care documenting best practices and surveying third party payers and Medicaid about reimbursement.

## IV. 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**

To date the workgroup has conducted four 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, Center 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 and their organizational affiliations mentioned in the *Introduction*, 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
- 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 Medical Center
- League of Women Voters
- State Council for Persons with Disabilities
- United States Department of Veterans Affairs
- Delaware Nurses for Life

### **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 our [website](#) and is also included in this report as Appendix B.

Resource	Summary of Findings
<b>Institute of Medicine (2014). Dying in America, Improving Quality and Honoring Individual Preferences Near the End of Life</b>	<p>This report from the Institute of Medicine (IOM) provided guidance to the workgroup through the past four months and helped inform the development 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.</p>
<b>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.</b>	<p>This report 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. Delaware received a B on the report card, indicating that 75% state’s hospitals reporting a palliative care team.</p>
<b>Delaware Advance Health Care Directive</b>	<p>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.</p>
<b>DMOST Legislation – Delaware House of Representatives 148<sup>th</sup> General Assembly, Bill No. 64</b>	<p>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 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.</p>
<b>Palliative Care Council Survey</b>	<p>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</p>

Resource	Summary of Findings
	funding or budget increases. One-third plan to offer 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%).
<b>Five Wishes</b>	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. 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.
<b>The Conversation Project</b>	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 Delaware-Specific Data

Data from the Delaware Health Statistics Center allowed for a discussion around where people die in Delaware - inpatient setting, an outpatient (emergency room) setting, nursing home, individual's residence, hospice care or other. Similar information from the Centers for Disease Control and Prevention enabled a comparison of Delaware statistics against national data. Both Delaware and national data showed a steady downward trend in the number of individuals dying in hospitals and an exponential increase in the number dying in hospice, which likely reflects the increased availability of hospice facilities over the past decade.

Due to a general paucity 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 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 is included as Appendix C of this report.

## V. Detailed Recommendations

This section expands upon the table of recommendations presented in section II of this report to include further description and primary findings associated with 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 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.

Below are key findings and recommendations associated with each of the above areas.

### 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, concern about the taboo surrounding discussion of death and dying and consumer fears about being pushed toward treatment decisions that may not align with 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 emphasize the need for education about what it means to be a surrogate and/or 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 end-of-life and palliative care and between palliative and hospice care.
- ❖ **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 that they were consenting to forgo life-saving measures in the event of a serious medical incident.
- ❖ **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 ‘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.

- ❖ **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, Honoring 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.

Recommendation	Responsible Party	Timeframe
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:	HCC/End Of Life Coalition/DCHI	
<ul style="list-style-type: none"> <li>Standardized educational materials about palliative and end-of-life care disseminated through multiple channels</li> </ul>		
<ul style="list-style-type: none"> <li>Formal encouragement and support to civic 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</li> </ul>		
<ul style="list-style-type: none"> <li>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, culturally sensitive</li> </ul>		
<ul style="list-style-type: none"> <li>Use of new and existing tools, forms and mobile applications</li> </ul>		
<ul style="list-style-type: none"> <li>Emphasis on the role of palliative care in improving quality of life whether we are seriously and/or terminally ill</li> </ul>		
<ul style="list-style-type: none"> <li>Specific support and resources for those who may have responsibility for carrying out end-of-life decisions on behalf of someone else</li> </ul>		

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.
- ❖ **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.** Specific guidance and supports may promote more frequent and 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 as well as expanding palliative and end-of-life programs present an opportunity to educate providers and consumers about the important consultative role of the health care provider. Individuals will consider 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 will help clarify treatment choices among patients, clinicians and loved ones.** This is especially true when other family members and decision makers are included in these conversations.

Recommendation	Responsible Party	Timeframe
1. Support and monitor progress toward inclusion of end-of-life and palliative services and supports in the care planning process.	HCC/End of Life Coalition/DCHI	
2. Include end-of-life and palliative care issues in the DCHI's workforce learning and relearning curriculum		
3. Include end-of life and palliative care issues in the work of the DCHI's Graduate Health Professional Consortium		

4. Specifically promote palliative and end-of-life care education as a means to meet continuing education requirements for providers at all levels.	Professional organizations	
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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, chronic illnesses may struggle to access the care and support services they need to thrive outside the hospital setting. 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.
- ❖ **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.** Additionally, patients and families may not be aware of palliative care services or know how to initiate accessing them. 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.

Recommendation	Responsible Party	Timeframe
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:		
<ul style="list-style-type: none"> <li>• Adoption of nationally-recognized professional and program standards where available</li> <li>• Creation of Delaware-specific program and professional guidance where appropriate to assure that issues of individual abilities, culture, and language are adequately addressed</li> </ul>		
2. Facilitate coordination among Delaware's hospitals and providers as they develop programs and resources related to palliative and end-of-life care		
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		
4. Review existing policies prohibiting home care service providers from administering medication to patients		
5. Explore mechanisms to make patient wishes readily accessible in a variety of settings		
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		
7. Develop supports to mitigate the impact on family members who leave or reduce employment to care for a loved one		

[Other recommendations to support comprehensive health care services to Delawareans with advanced and serious illnesses](#)

**KEY FINDING: Delaware-specific data related to the quality, availability and utilization of end-of-life and palliative care services is not readily available.** 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	Timeframe
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:		
<ul style="list-style-type: none"> <li>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</li> </ul>		
<ul style="list-style-type: none"> <li>Evaluation of data available through the Delaware Health Information Network (DHIN), Behavioral Risk Factor Surveillance System (BRFSS) and other available data</li> </ul>		
<ul style="list-style-type: none"> <li>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</li> </ul>		

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

Recommendation	Responsible Party	Timeframe
1. Formally link current activities related to end-of-life and palliative care with ongoing health system transformation including, at minimum, the Advance Care Planning working group of the Delaware Healthcare Association (DHA), the Delaware End-of-Life Coalition, the Delaware Health Care Commission and the DCHI.		
2. Primary responsibility for implementation and monitoring of the recommendations contained in this report should lie with the HCC until formal linkages are in place as outlined above.		

# APPENDICES

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## Appendix A.

### Workgroup Meeting and Public Listening Session Participants

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.

#### Workgroup Members

Jill Rogers, *Chair*

Director, Division of Services to Aging and Adults with Physical Disabilities

Michael Alexander, M.D.

Medical Society of Delaware

Rep. Paul Baumbach

Delaware State Representative, 23<sup>rd</sup> District

Keagen Brown

President, Delaware End-of-Life Coalition

Tim Gibbs

Executive Director, Delaware Academy of Medicine

Allison Gonzalez

Palliative Care Liaison, St. Francis Hospital

John Goodill, M.D.

Director, Palliative Care Education and Outreach, Christiana Care Health System

Daniese McMullin-Powell

State Council for Persons with Disabilities

Susan Lloyd

President and CEO, Delaware Hospice, Inc.

Lexie McFassel, Esq.

Public Guardian, Office of the Public Guardian

Julane Miller-Armbrister  
Executive Director, Delaware Center for Health Innovation

Tim Rodden  
Director of Pastoral Services, Christiana Care Health System

Wayne Smith  
President and CEO, Delaware Healthcare Association

Laura Waterland, Esq.  
Senior Staff Attorney, Community Legal Aid Society

Session Participants

Megan Alexander

Jackie Armstrong

Kit Angell

Maria Ash

Judy Bernstein

Nick Bernstein

Ruth Bochnowski

Cheryl Bolinger

Sarah Carmody

Rich Collins

Kathy Collison

Mike Cordrey

Robert Detrick

Larry DeFrancisco

James H. Dunde

Sean Dwyer

Cyndy Fanning

Sally Frechette

David J. Friedland

Keith Goheen

Nate Griffin

Wendy Griffin

Michelle Y. Griffith

Peter Hartrauft

Joann Hasse

Loretta Higgins

Kyle Hodges

Luanne Holland

Laura Howard  
Jan Hunsucker  
Jeff James  
Kathy James  
Richard N. Jester  
Chris and Deforest Johnson  
Jonathan Kaufman  
Joan Kinsey  
Vicky Kleinman  
Moonyun Klopfeustein  
Peter Kopf  
Lyra Lascano  
Theresa Latorre-Tegtmeier  
Margaret Lawson  
Jan Lee  
Debra Lennox  
Teresa LoPorto  
Cheyenne Luzader  
Jim Luzader  
Pat Maichle  
Bess McAneny  
Shawn McCullough  
Barbie McDaniel  
A. McDermott  
Ingrid McDonald  
Kelsey Mellette  
Melissa Miller  
Dave Mills  
Lloyd Mills  
Susan Mumford  
John Nichols  
Merry Norfleet  
Cornelia Northway  
Janet Orlando  
Alex Parkowski  
Cimone Philpotts  
Cheryl Precourt  
Diana Price  
Jen Rini  
David Risseuw  
Kate Rohner

Esther Shelton  
Eileen Sparling  
Sandy Spence  
Angela Steele-Tilton  
Nicole Thj  
Jacqueline Thomas  
Jane Tiffany-Shields  
Marge Turner  
Yrene Waldron  
Casey Walsh  
Dee Whildin  
C. Robert Wilson  
Carolyn Zsoldos  
Silvia Zsoldos  
Linda Zubrowski

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## Appendix B. Annotated Bibliography of Resources

**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.

**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/filer\\_public/3c/96/3c96a114-0c15-42da-a07f-11893cca7bf7/2011-public-opinion-research-on-palliative-care\\_237.pdf](https://media.capc.org/filer_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 148<sup>th</sup> 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:

- 1) Provide coverage for comprehensive care for individuals with advanced serious illness who are nearing the end of life.
- 2) Develop standards for clinician-patient communication and advance care planning that are measurable, actionable, and evidence based.
- 3) Establish the appropriate training, certification, and/or licensure requirement to strengthen the palliative care knowledge and skills of all clinicians who care for individuals with advanced serious illness.
- 4) Finance medical and social services that support the provision of quality care consistent with the values, goals, and informed preferences of people with advanced serious illness nearing the end of life.
- 5) Provide fact-based information about care of people with advanced serious illness to encourage advance care planning and informed choice based on the needs and values of individuals.

**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](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 following hospitals are providing palliative care:

- 90% of hospitals with more than 300 beds
- 97% of teaching hospitals
- 90% of Catholic Church operated hospitals
- 77% of nonprofit hospitals

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: randomised 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 randomised 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 randomised 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.

## Appendix C.

### 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 major 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.
  - EOL 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 50<sup>th</sup> 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.