

**Delaware Health Care Commission – End of Life Workgroup
Annotated Bibliography of Resources to Date**

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

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:

- 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

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 Gundersen'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.