
Everybody Dies:

A Guide to Making Hard Conversations a Little Bit Easier

A Hanley IX Product by

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Introduction

My doctor asks me about end of life care every time I see him. I guess it's because I've been real sick for a while. But what I don't get is when are we going to actually make a plan? At some point, don't we have to stop talking about what it means to die...and actually figure out the details of what this will look like for me?

As a provider, I find myself confused about the difference between palliative care and hospice. That's one of the main reasons I feel uncomfortable discussing it with my patients.

Looking at a patient and labeling them as a candidate for "palliative care" can be difficult. When I look at the whole patient, personality, energy level, engagement with their family and their community, it can often create a challenge in not only referring them to a specialist, but having the discussion of end of life with someone who seems very much alive

What Is Palliative Care?

In 2008 CMS defined palliative care as patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice. It is worth noting palliative care can be provided right along with the medical treatment a patient is receiving for a serious illness.

Palliative care is supportive care that can start simply with a conversation about what matters to the patient.

This booklet will discuss:

- *Who should be on the Palliative Care Team*
- *Ways to begin the conversation with patients*
- *Give a few examples of tools being used in Maine that providers have found helpful*
- *A list of partners and resources both local and statewide that can assist as you continue to work to incorporate Palliative Care strategies into your practice*

Preparer's Note: This is not meant to be a comprehensive list of tools, but to state some promising practices and work as a compliment to the work that is already being done.

Palliative Care Survey Highlights

In an effort to better understand current practices regarding palliative care in the outpatient setting, we circulated a survey to teams working in primary care, nephrology and infectious disease. Ninety-three individuals responded to the SurveyMonkey® tool that we shared via email in late January/early February of 2016. While 63% of survey respondents were MD/DO/NP/PAs, we also received responses from a representation of those working in outpatient healthcare settings including LCSWs, Psychologists, Medical Assistants, LPNs, Practice Managers and Administrators.

Among respondents, 42% endorsed “sometimes” having conversations with patients about palliative care. 34% responded that they never or rarely spoke to patients about this service.

Of those talking with patients about palliative care, 24% stated they did not use a specific tool to initiate conversations. Of those using a tool, 44% described using Advanced Care Directives and the next most common approach was the Living Will or POLST (26%).

More than half of the respondents (54%) indicated they had conversations with patients about palliative care “regularly when appropriate.” However, respondents clearly indicated “patient readiness” (22%) and “time constraints” (21%) as significant barriers to better addressing palliative care in the health care setting.

At the conclusion of the survey, we used an open-ended format to query respondents about recommendations for better addressing palliative care in the primary care setting. Themes from these responses include increased training opportunities for providers, more education for patients and promoting the existence of available specialty palliative care resources.

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Building the Palliative Care Team in the Primary Care Setting



Due to the complicated nature of palliative care and the challenges many providers face in finding not only the time itself, but also the right time to breach the subject, it may be helpful for an office to build a team of support. The above graphic shows a potential structure in which a Primary Care office could build a team around the patients palliative care needs.

First Level: *Patient/Primary Care Provider*

Both have an established relationship, but may find barriers (time, comfortability, etc.) in having initial palliative care discussions.

Second Level: *Patient, Primary Care Provider, Patient's Support Person, Behavioral Health Staff*

With the addition of a behavioral health staff member, the emotional aspects of end of life care may be more thoroughly addressed. Through a warm hand off, the role of palliative care may be further explored to help the patient better understand their options. An additional supportive person in the patient's life may also help alleviate the same stressors that the patient may have had addressing end of life issues with their provider.

Third Level: *Second Level members and other PCP office workers as needed*

By bringing on more and more staff with knowledge of palliative care, there will be more opportunities to systematically add ways to engage patients and other staff in palliative care discussions. These discussions will de-stigmatize the conversations and build a stronger role for palliative care in primary care settings.

Fourth Level: *External Partners and Resources*

In reality, not every primary care setting will have the ability to build a team around this work, or patients may most benefit from specific services. The fourth level is separate for this reason. For some, engaging partners and specialists may be the next step in meeting the patient's needs. However, for others (depending on patient load and size of office) it may be most realistic for them to refer to palliative care specialists at other offices or hospitals in their areas.

As palliative care continues to move forward with its place in primary care, continue to think about what staff members may be included in the team approach.

Tools to Facilitate Discussion about Palliative Care in the Primary Care Setting

In conversations with stakeholders and through a review of the literature, there is general agreement that starting the conversation about palliative care is the most important step. For many clinicians, there is reluctance to do so. Here are examples of approaches that might move you towards “starting the conversation.”

Many clinicians avoid having conversations about palliative or end of life care due to of lack of confidence in determining a prognosis for patients. *Eprognosis* is an app developed by geriatricians at UCSF utilizing prognostic indices for older adults who do not have a dominant terminal illness. Their website also provides links to indices for a dominant terminal illness such as advanced dementia, cancer, or heart failure.
www.eprognosis.ucsf.edu

Consider a systematic approach

Example: For all patients over the age of 50 make a point of annually discussing advanced care planning. Start the conversation by asking, “Have you ever thought who you would like to make decisions for you if you were unable to make those decisions for yourself?” For those with terminal and chronic conditions, set aside time to ask about their understanding of their own illness, and their prognosis.

When entering an office visit with a patient, ask yourself the question, “Would I be surprised if this patient were to die in the next 12 months?” If the answer is no, there is a good opportunity to start a conversation about palliative care.

It’s important to note it’s never too early to start the conversation. Providers may find the following questions helpful to ask:

Do you understand the seriousness of your illness?

Do you want information about prognosis?

What goals are important to you? What worries you? Who is your support person?

Talking with patients will help them with their Advance Care Planning and provide them with a sense of relief and improved quality of life.

A Note about Billing for Palliative Care:

Beginning in January 2016 Medicare will reimburse healthcare providers for advance care planning (ACP) discussions with patients. The ACP discussions must be face to face conversation with the Medicare patient, family member(s) and/or surrogate. The CPT code 99497 (wRVU 1.50) first 30 minutes and 99498 (wRVU 1.40) each additional 30 minutes, may be billed together and are not limited. Any Medicare beneficiary is entitled to this service. The service and billing may occur at the same time as any evaluation and management visit or wellness visit. The service may be delivered by a provider, nurse practitioner and other staff under the order and medical management of the beneficiary’s treating provider.

Tools to Better Address Palliative Care in the Primary Care Setting

When surveying teams working in primary care, individuals who responded that they were having some amount of conversations regarding palliative care, overwhelmingly described using tools that address advanced care planning (which may or may not specifically address engagement in palliative care).

Documents

Advanced Care Directives /Living Will

Under Maine law, the term “advance directive” means any spoken or written instructions one gives about the health care he or she may want if a time comes when he or she is too ill to decide.

Here is a link to the Maine Health Care Advance Directive Form:

**<http://www.themha.org/policy-advocacy/Issues/End-of-Life-Care/advdirectivesform.aspx>
(updated 2008)**

Five Wishes

Five Wishes is one of the most popular Living Will documents in the United States because it’s written in everyday language and helps people express their wishes in areas that matter most — personal and spiritual in addition to medical and legal. It also helps describe what good care means to an individual, separate from the context of illness. In 42 states, including Maine, residents can put their end-of-life wishes in their own words, rather than require state-written documents.

Here is a link to the Aging with Dignity website (the organization behind Five Wishes):

<https://agingwithdignity.org/five-wishes/individuals-and-families>

The POLST (Physician Orders for Life-Sustaining Treatment)

The POLST form is a clear and specific set of medical orders that express a patient’s wishes for care near the end of life. The form is printed on bright lime green paper and signed by both a health care professional and the patient. The POLST is not for all adults, but for patients with an advanced illness or frailty which may shorten life. It is a signed medical order that a health care team can act upon and therefore distinct from an Advance Directive. It is generally recommended that a patient have an Advance Directive and a POLST.

Here is a link to Maine Hospice, the umbrella organization for the Maine POLST Program:

www.polstmaine.org

Tools to Better Address Palliative Care in the Primary Care Setting

Resources for Developing Skills and Increasing System Capacity

The Serious Illness Care Program

The Serious Illness Care program facilitates appropriate conversations between clinicians, seriously ill patients and their families.

Drawn from best practices in palliative care, the intervention provides guidance for clinicians to initiate these difficult conversations in the right way, at the right time. Patients then have the opportunity to make informed choices that reflect their values, reduce suffering, enhance family well-being and improve quality of life.

Here is a link to The Serious Illness Care Program:

<https://www.ariadnelabs.org/programs/serious-illness-care/>

The Conversation Project

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life. The Resource Center includes tools for health facilities to engage patients.

Here is a link to The Conversation Project:

<http://theconversationproject.org>

VitalTalk

VitalTalk is a nonprofit with the mission of nurturing healthier connections between patients and clinicians. They specialize in developing and facilitating advanced communication skills courses and faculty training courses focused on balancing honesty with empathy when discussing serious illness and end of life care

Here is a link to VitalTalk:

<http://www.vitaltalk.org>

Respecting Choices Advance Care Planning – Gundersen Lutheran Medical Foundation

A comprehensive Advance Care Planning program that advocates four key elements: training of health professionals and others to skillfully facilitate ACP discussions, developing community and organizational systems and practices to incorporate ACP into routine of care, designing effective patient and community ACP engagement materials, and monitoring outcomes with continuous quality improvement methods.

Here is a link to Respecting Choices Advance Care Planning:

www.gundersenhealth.org/respecting-choices

Patient Oriented Tools

Palliative Care: What You Should Know

This patient focused handout is a tool used to introduce palliative care to patients and their families.

The handout describes the Who, What, When and How basics of palliative care in a way that is accessible, open ended, and allows for further discussions to be had with providers regarding the role of palliative care as a medical service

Here is a link to Palliative Care: What You Should Know

<https://getpalliativecare.org/wp-content/uploads/2012/09/WhatYouShouldKnowHandoutRevised.pdf>

Palliative Care: Choosing Wisely

A patient oriented handout developed through partnership with Consumer Reports and the America Academy of Hospice and Palliative Care Medicine. This offers a brief overview of palliative care and offers “tips” to help patients get the best medical care near the end of their life

Here is a link to Palliative Care: Choosing Wisely

<https://www.choosingwisely.org/patient-resources/palliative-care/>

Palliative care is an ever-evolving field, and sometimes it can be difficult for patients and providers to know where to turn for up to date information and support. Here are some agencies in your area that are providing palliative care programming and information.

Statewide

Maine Association of Area Agencies on Aging

www.maine4a.org

Veterans Association - Maine Health Care System

www.maine.va.gov

Central Maine Medical Center

<https://www.cmmc.org/palliative-care>

Eastern Maine Medical Center Supportive Care Program

<https://emmc.org/Supportive-Care.aspx>

Maine General Medical Center Palliative Care Program

<https://www.maine-general.org/Pages/Care-and-Services-A-Z/Palliative-Care.aspx>

Maine Medical Center Palliative Care Program

<http://www.mmc.org/palliative-care>

Mercy Hospital

<https://mercyhospital.org/Healthcare-Services/Palliative-Care/Palliative-Care.aspx>

Mid-Coast Hospital

<https://www.midcoasthealth.com/palliative-care/>

Pen Bay Medical Center

<https://www.penbayhealthcare.org/palliative/>

St. Joseph Hospital

<http://www.stjoeshealing.org/our-services/specialty-services/palliative-care>

Southern Maine Health Care

<http://www.smhc.org/care-and-services/palliative-care>

VNA Home Care

<http://vnahomehealth.org/>