

Advanced Care Planning: its for everyone

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Introduction

In the Fall of 2014, Medicare was again considering reimbursement to health care professionals for providing Advance Care Planning (ACP) services.

Atul Gawande, a physician and leading writer on public health issues had released his book Being Mortal exposing the reality of end of life care and asking the question what should health care look like at end of life.

National Public Radio recorded a segment with Dr. Bernard Hammes, a medical ethicist, who 20 years ago after supporting so many people in making the difficult decisions for loved ones at end of life, decided he would do something about it

In 2012 Holy Cross Hospital development department staff was just beginning to ask how to support people in completing advance directives.

In 2014 Elizabeth Crittenden-Palacios, inspired by the NPR interview with Dr. Hammes to take a step forward. She decided, with support from key stakeholders to begin to research initiatives to improve completion of advance directives. This report is the result of this initial investment.

“While more than 80% of all Americans believe they want to spend their last days at home, only 24% die at home. The majority dies in hospitals or nursing homes. The end of life often means being attached to machines pharmaceuticals and often dying with strangers (medical providers) rather than with family members.”

--Angelo Volandes from The Conversation

What is Advance Care Planning

Advance care planning is currently receiving a lot of attention. But, ACP is nothing new.

In 1990 the Federal government enacted the Federal Patient Self Determination Act in which health care users were given the right to have a say in how they want to be treated if they become incapacitated.

In 2009 efforts to include reimbursement for ACP planning into the affordable care act were ended by the labeling of these discussions as “death panels”

Today the American Medical Association continues to advocate to Medicare for reimbursement to health care professionals for providing this service. Amazingly,

private insurers are taking the lead and beginning to reimburse physicians and their staff for engaging in the ACP process.

Advanced Care Planning begins with a simple question: how do I want to spend the last few months of my life? This is important. ACP is about living not about dying.

But understanding the process of death and the many ways in which modern medicine has been able to prolong life is key to making decisions about the future. Advanced Care Planning is the process by which a person considers their options for end of life care, in particular, planning for the time when they may be unable to communicate their wants and needs.

Advanced Care Planning can happen at any time, but most often it occurs when people become elderly, sick or both. Experts believe that Advanced Care Planning can occur at any time, and best completed before a health care crisis

Many believe intuitively that discussing end of life may lead to hopelessness and a shortening of the will to live. Studies though have found the opposite to be true. Planning decreases a persons and their families stress and increases the quality of end of life.

Advance Care Planning hits the ground

Important questions to ask from The Conversation by Angelo Volandes

- What kinds of things are important to you in your life?
- If you were not able to do the activities you enjoy, are there any medical treatments that would be too much?
- What fears do you have about getting sick or medical care?
- Do you have any spiritual, religious, philosophical or cultural beliefs that guide you when you make medical decisions?
- If you had to choose between living longer or having a higher quality of life, which would you pick?
- How important is it for you to be at home when you die?

ACP results in legal documents that clearly articulate both in broad terms and specifically a persons wishes for end of life medical treatment and intervention.

Advance Directive: These are the written wishes of the person. Often called a living will, the directive does not go into effect until the person is deemed incapable of making decisions regarding their health care options. Most often completed with the help fo attorney's, this is not a requirement. In New Mexico, advance directives do not need to be notarized and can be completed on one's own or with the help of health care provider.

Durable Power of Attorney for Health Care: This is a legal form most often completed with the aid of an attorney. A durable power of attorney appoints a Health Care Representative (or agent or proxy) to make decisions for the individual if they are deemed unable to speak for themselves. For a health care agent, a strong advance directive is their guidebook for making decisions that they believe are what an individual would like at the end of life.

Physicians Orders for Life Sustaining Treatment (POLSTt) These are legal forms completed with a physician which describe specific treatment decisions at the end of life. This form is often the final form in an ACP process.

Advance Care Planning Initiative

Why?

Outcomes for people with advance directives

- Increases the likelihood that individuals receive the care that they prefer at the end of life
- Reduces depression and anxiety in family members
- Increases family satisfaction with the process of care.
- May contribute to decrease in health care costs for health care systems and the communities they support.

Across the country states, counties and communities are undertaking initiatives to increase the number of their citizens/members who have Advance Directives.

The question is how do we have The Conversation?

What is involved in an Initiative

Community Education & Outreach

- Education about medical treatment at end of life
- Information on how to complete an advance directive
- Forms and guides for completing advance directives
- Web sites with access to information and terms
- Events to promote ACP
- Video stories

Direct Programming

- Opportunities for individuals, families and neighbors to meet and discuss end of life with trained facilitators
- Easy access to forms and knowledgeable people who can guide people in completing advance directives.

Systems Work

- Training for health care providers, etc in how to encourage completing ACD
- Policies and procedures for engaging patients in the conversation and types of forms accepted by the institution
- Aligning of forms and formats for guiding conversation across health care spectrum

Infrastructure

Leadership

- Most initiatives are lead by the local medical society or health care coalition.
- Most initiatives are governed by a committee of people who represent a broad array of community, health care and business interests. These efforts are never done in isolation or by a single group.
- One or more organization give support by providing staffing to meetings and coordinating of efforts

Key Elements

- Web sites
- Partnership with local media outlets
- Connection to state and national efforts to promote and align Advance Care planning
- Partnership with faith leaders and communities
- Cadre of volunteers trained in holding conversations and supporting completion of documentation

Funding

- Most initiatives are funded by a combination of local philanthropy, medical associations and systems, health care plans and national foundations

National Efforts

National Hospice and Palliative Care Organization is a Non-Profit Membership organization representing Hospice and Palliative care professionals. Their work is primarily in advocacy and providing resources and education across the wide range of issues. They are supporters of National Health Care Decisions Day, Advocate for national legislation to improve people's ability to make their own decisions for healthcare, and create large media campaigns.

Important to this effort is their Caring Info, formerly called Caring Connections, resource section. Here they provide information and resources for Advance Care Planning including:

- Conversation guides
- State by state information on how to create advance directives and POLST forms
- Information on end of life treatments
- Guides for clinicians

Their simple outline below is an excellent guide for promoting ACP

"It's about how you **LIVE**"

- Learn about options for end of life services and care
- Implement plans to ensure wishes are honored
- Voice decisions to family, friends and health care providers
- Engage in personal or community efforts to improve end-of-life care. Many resources for coalition building, community education and outreach to stakeholders

The Conversation Project Founded by Ellen Goodman in collaboration with Institute for Healthcare Improvement and colleagues in media creates tools and provides resources to encourage people to have conversations about end of life care. They, too, participate in April in national efforts and provide seminars.

They have an excellent web site that is clear concise. On the web site are video stories, newsletters and resources. Also on the website is a downloadable "Starter Kit" for individuals that guides how to have conversations with family and friends and complete directives

The Conversation Project also recently started the **Death Over Dinner**. This national event encourages having a family dinner and conversations about end of life planning. Included are guides for how to facilitate a conversation and recipes for comforting food.

National Health Care Decisions Day April 16, 2016 is a day devoted to providing information and encouraging people to complete advance directives. All over the country health care organizations to create their own community appropriate formats that promote ACP and provide uniform tools to individuals. In New Mexico Christus St. Vincent and Presbyterian Health Care have been active participants in the NHCD Day.

Death Café is a grassroots effort to provide opportunities for people to come together and discuss death. Called social entrepreneurship, Death Café organizers are asked to follow a basic set of guidelines and provide cake and tea for participants.

State Level Initiatives

Across the country states are Medical Societies, Health Care organizations and Community members are joining together to promote Advance Care planning. Leading this charge is Minnesota and their initiative Honoring Choices©

Honoring Choices began seven years ago

- Minnesota Honoring Choices
- Compassionate Care Coalition of CA
- NM MOST



County Level Initiatives

- Sonoma

- Napa

Health System Initiatives

- Gunderson

Christus St Vincent

Through efforts from the Palliative care department, Christus St Vincent Hospital recently approved the use of the NM MOST form within their facility. They worked with Lorrie Griego of NM MOST and received the train the trainers training in how to use the NM MOST. They went on to train many people in the hospital, in local nursing facilities and in local practices in using NM most. While they still use the 5 Wishes form, the NM MOST simple and concise format works well within their environment.

Now Christus St Vincent has a committee working on promoting advance directives. The committee is made up of palliative care staff, nurses, members of the ethics committee, an ex board member, faith provider and a person with strong connections to the state legislature. The committee reports to the hospital ethics committee.

This year Christus St Vincent joined the National Health Care Decisions Day and held an event where they provided information and support to individuals interested in advance directives.

Taos: Information from Key Informants

The Form

- Advance directives are being completed in lawyers offices, at intake in the Living center and with the hospice social worker
- While the 5 wishes was mentioned most often, each of entity uses a different form
- All believe that people need a knowledgeable and supportive person to help people complete the form.
- There are many different names and different forms with different sort of uses: DNR or Do Not Resuscitate, Living Will, POLST and providers say that it is not clear to individuals the differences between them or why they many need multiple forms.
- Providers say that advance directives and advance care planning is important to be done but people don't always discuss this with the people who need to know that they have them: their families.
- Informants also remark that it isn't enough to complete the forms, they must give them to their families, health care agent, doctor and local hospital. Providers also encourage that people care a card in their wallet to let EMS workers and emergency department providers know that they have a directive.

The Process

- Those in the know believe that most people that have advance directives have completed them with attorneys. All attorneys say that they incorporate advance directives into their estate planning process. All believed it would be unethical for them to not do so.
- Some people brought up that if a person doesn't believe that they need to have a will they don't know how they don't know that they need to complete advance directives. The tie between estate planning and advance directives leaves many people in dire need of a directive without.

The 5 wishes is a good psycho-social format but people need support to complete it."

"When in crisis the nurse doesn't have time to read through a multipage document to see what a patient wants"

On the front line: the providers

- Medical providers uniformly believe that the conversation needs to begin in the primary care setting, but this also requires at least one if not more lengthy conversations. The primary care doctors often do not have the time with patients.
- Providers say that many patients do not understand what an advance directive would or would not do or that they can be changed.
- Many believe that during a crisis is NOT the right time for the conversation. The patient and family are too caught up in the moment and too scared to be able to take in the information. The form often is left behind.

- What is needed is better education about end of life treatments. Most people don't know what the treatments are really like, the trauma .

Some quick facts

- Alcohol related chronic disease death rate 52/100K btw 2009 -13
- Heart disease death 129
- Stroke death 26 2011-13
- Diabetes death 20 2011-13
- Life expectancy average 87

"Most people have unrealistic expectations about what end of life treatments can accomplish. The success rate is much much lower than what they see on TV."

What can be done?

Ideas from Key Informants

- Information and support for completing advance directives at Health fairs
- Seminars with panel discussions about advance directives
- PSAs
- Get primary docs to talk

What we know works

- Respecting Choices

“At my last job at a big health care institution they asked all of the staff to complete advance directives. I really understood what I was asking of my patients. Now I have had a directive for 10 years and I tell this to my clients”

“I think we ought to involve people working in Human resources. While you are learning about Life Insurance you should learn about advance directives.”

Who can help? Who should help?

Common to all the initiatives is an organizing committee. This committee usually includes nursing staff, physicians, board members, faith leaders, passionate community members and policy leaders. When speaking with leaders from other initiatives they all said the first step is forming a committee.

Most of the initiatives are managed/lead by a medical society, large health care institution or community coalition.

How to get started

- Build a steering committee of people with experience, people with passion and people with connections.
- Contact Christus St Vincent and NM MOST. How can Taos be involved or benefit from others work and experience?
- Each health care entity uses a different form that fits their needs. Does this work for the individuals?
- Get to know what others are already doing. Participate in a “Death Café” meeting.
- Organize an event for national Health Care Decisions day April 16, 2016 www.nhdd.org/#welcome
- Connect with Respecting Choices
- Advance directives are part of the language in the health care industry. How many people working in this industry in Taos have a advance directive of their own? Is this a place to start?