Advance Care Planning: What You Need to Know

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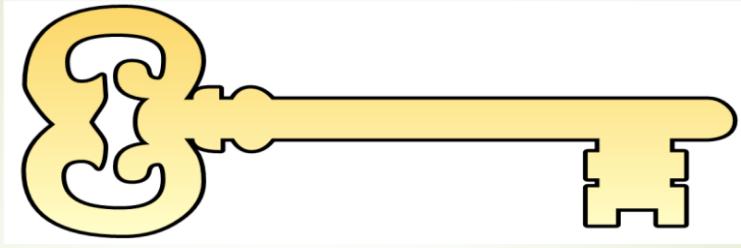
Objectives

- Understand the importance of Advance Care Planning
- Acknowledge the wishes of the person
- Facilitate conversations between the person, healthcare provider(s), and families



Raising awareness of the opportunity to write advance directives is important, but raising professional awareness of the need to respect them is key to improving the care provided to dying patients.

- Dobbins (2007), p. 54

Relevant Legal Precedent

- Karen Ann Quinlan (1976): Family sought to remove daughter from ventilator
- Nancy Cruzan (1990): Family wanted to discontinue daughter's feeding tube
- Terri Schiavo (2005): Husband versus parents and others

A Little History

- Patient Self-Determination Act (PSDA): Implemented in 1991. The intent is to promote personal autonomy by encouraging patients to participate in future planning through preparation of advance directives.
- Came about as a result of the Cruzan case (Cruzan v. Director, Missouri Dept. of Health, 1990)
- Mandates that all HC institutions receiving Medicare and Medicaid funding inform patients about their right to participate in HC decisions, including the right to have an AD

Healthcare Directives

- Living Will
- Advance Directive
- Designation of durable power of attorney for health care (DPOA-HC)
- MN law changed in August 1998; combined the living will and DPOA-HC into one document called a Health Care Directive (HCD)

What is Advance Care Planning?

- Advance care planning (ACP) is an organized process of communication to help individuals understand, reflect upon, and discuss goals for future healthcare decisions in the context of their values and beliefs.
  - Hammes & Briggs, 2007

What Advance Care Planning Can Do

- When the process is done well, it has the power to produce a written plan (a healthcare directive) that accurately represents an individual's preferences and thoroughly prepares others to make healthcare decisions consistent with those preferences.

- Emphasis is on the process of planning, NOT the completion of a document.

Steps in the Process of Advance Care Planning

- Contemplation of one's treatment wishes
- Discussion of ACP with family or friends, especially with your chosen healthcare agent
- Discussion of ACP with one's health care provider (usually physician)
- Documentation of one's wishes in an advance directive

The person you choose as your healthcare agent should be…

- Someone you can talk to and discuss your values and goals with
- Someone willing to accept this responsibility
- Someone able to follow your wishes
- Someone able to make decisions in stressful situations

Barriers to Advance Care Planning

- Perceiving ACP as irrelevant ("I'm too healthy, too young"; want to leave health in God's hands)
- Personal barriers (Preferring to leave the choice to others or discomfort discussing ACP)
- Relationship concerns (Not having an available surrogate decision maker)
- Information needs (Inadequate knowledge of health care options)
- Health encounter time constraints (Too many other issues to discuss with provider)
- Problems with advance directives (Needing help understanding the forms)

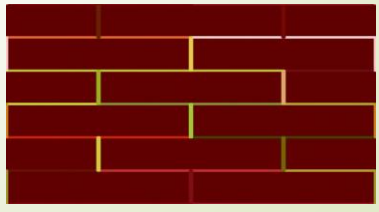
(Schickedanz et. al., 2009)

More Barriers

- Mistrust of health care system
- Trust that the doctor will know what to do
- "Family members know what I want" but no conversations with them
- Not asked about ACP
- Concerns that harm will come by discussing ACP
- Lack of knowledge of ACP
- Timing: Hospital admission or acute illness make it difficult to make decisions

Provider Barriers

- Some think it is only about discussing DNR status
- Stress of situation, such as admission to hospital
- Relegated to an admission check box system: "Do you have an advance directive" Yes/No; May be followed by "Would you like information?"
- Personal lack of knowledge related to ACP, or finding it awkward initiating a discussion
- Not enough time
- Lack of privacy for discussion
- Feeling patients are not sick enough to warrant a discussion of that intensity
- Insurance



What Might Happen if there is No Plan

- Medical under or over treatment
- Burden family members who must assume decision-making without expressed communication about treatment goals and preferences,
- Can cause conflict among family members and between family members and health care providers

End-of-Life Care

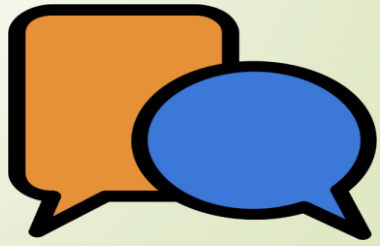
- Provider Orders for Life-Sustaining Treatment (POLST) form
  - Originally developed in 1994 at the Center for Ethics in Health Care of Oregon Health Science University. The POLST form is designed as a physician's order
  - It requires the signature of both the physician and the patient or legal surrogate
  - MN form is currently being updated
  - http://www.mnmed.org/KeyIssues/POLSTCommunications/tabid/3291/Default.aspx

What Can Providers Do?

- Be aware of resources in your community and on-line
- Initiate the discussion
- Inquire if clients, patients or others have Health Care Directive and if not discuss the importance of ACP
- Elicit understanding of and discuss prognoses for disease processes
- Acknowledge religious/spiritual practices and include when discussing ACP
- Understand anxiety concerning ACP
- ACP can reduce stress for surrogate decision makers
- Have you completed your own ACP?

The Discussion

- Discuss the topic over multiple visits
- Schedule a dedicated ACP visit, if possible
- Discuss friends' or family members' previous end-of-life experiences
- Respect where the person is in the process and maintain an open dialogue
- Provide written materials
- Information on community/local resources



- People will engage when they are ready or when circumstances warrant
- Stay current in your understanding of ACP
- Review documents periodically
- Be sure they provide copies to their other healthcare providers, hospital, loved ones, etc. so that the information is available when they need it

Billing for Advance Care Planning Services Under Medicare

- As of January 1, 2016, under Medicare, ACP can be reimbursed
- *"Advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified health care professional; first 30 minutes, face-to-face with the patient, family member(s), and/or surrogate"*
- *For more information, click on the link below:*
- https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/PhysicianFeeSched/Downloads/FAQ-Advance-Care-Planning.pdf

If Someone Already Has A Health Care Directive…

- Ask when they completed it
- Ask who they discussed it with, if anyone
- Ask when they last reviewed it
- Ask what their understanding is of what they filled out
- Ask who they have given copies to
- Ask if they have experienced any health or personal changes since it was originally completed
- Ask where it is located
- Ask if they want to make any changes
- Ascertain if there any gaps in knowledge

When to Review

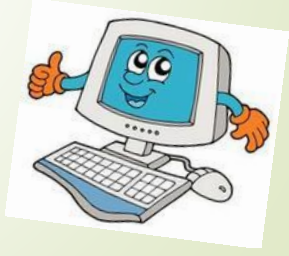
- You start a new **Decade** in your life
- You experience the **Death** of a loved one
- You experience a **Divorce** or other major family change
- You are **Diagnosed** with a serious health condition
- You experience a significant **Decline** or **Deterioration** of an existing health condition

How to Learn More

- Networking at the annual HCM Sharing the Experience Conference in July in Minneapolis
- National Share the Experience Conference in September
- MN Gerontological Society Annual Conference in April
- ACP facilitator classes through SCSU, Light the Legacy, and Honoring Choices

Online Resources

- www.honoringchoices.org
- www.lightthelegacy.org
- www.respectingchoices.org
- www.theconversationproject.org
- www.nhdd.org



Written Resources

- *Being Mortal: Medicine and What Matters in the End (2014)* by Atul Gawande
- *The Good Death: An Exploration of Dying in America* (2016) by Ann Neumann
- *The gray zone: When life support no longer supports life* (2013) by Deborah Day Laxson
- *We Know How This Ends: Living While Dying* (2015) by Bruce Kramer and Cathy Wurzer
- Gawande, A. (2010). *Letting go: What should medicine do when it can't save your life?* In The New Yorker http://www.newyorker.com/reporting/2010/08/02/100802fa_fact_gawande?currentPage=all

National HealthCare Decisions Day
April 16th

http://vimeo.com/36052824

NBC: Rock Center

A video resource that examines the impact of next steps ACP and quality of life.

http://video.msnbc.msn.com/rock-center/50112401

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The future depends on what we do in the present.

–Mahatma Gandhi