Advance Care Planning

Making Preparations in Case Life Changes Unexpectedly

ACP
ND
ADVANCED CARE PLANNING
OF NORTH DAKOTA

Purpose & Objectives

Purpose: To increase knowledge about the importance of having discussions about values, preferences and goals to improve quality of life while journeying through serious health conditions.

Objectives: At the end of this session, participants will be able to:

1. Explain the benefits of early discussion about preferences for care.
2. Describe the steps of the advance care planning process.
3. Describe the role of the patient, proxy (agent), clinician and others in advance care planning.
4. Identify approaches that can improve the health care agents' ability to make difficult decisions if called upon to do so.
5. Identify pitfalls and limitations in advance care planning.
6. Identify steps being taken by Sanford Health to create a culture where advance care planning conversations are normalized.

We Anticipate and Plan for Important Life Events

The process of dying is as natural as the process of being born.

Pregnancy is a developmental state that prepares us for birth, dying is a developmental phase of “undoing” or “unwinding”.

•Both of these phases take time

•Both have observable changes in the body

What is YOUR ideal vacation?

For some the ideal vacation is a ski trip in Colorado, for others it might be time at the beach. When planning we think about:

- Amount of time available
- Cost
- Get information
- Preparations (service car, buy tickets)
- Active or restful
- Alone or with others
- Others influence on the plan
- Energy we need to put in (driving, cooking, travel)
- Preferred surroundings

What is Advance Care Planning?

- ***Advance Care Planning*** 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.

- It has the power to produce a written plan (***Advance Directive)*** that prepares others to make healthcare decisions consistent with the patient's preferences.

A Staged Approach to Advance Care Planning

- *First Steps ACP* is part of routine care. The goal is to identify an agent. The focus is on permanent neurologic injury.
- *Next Steps ACP* is for patients with chronic, progressive illness. The goal is to understand the benefits and burdens of life-sustaining treatments within the context of their illness. The focus is to prepare the agent to make decisions if needed.
- *Last Steps ACP* is for those whose death within 12 months would not be a surprise. The goal is to make pro-active decisions about end-of-life care. The focus is to translate decisions into medical orders that follow the patient across all care settings.

5 Steps for Advance Care Planning

1. Become educated—it starts with being here today
2. Remove any barriers—get the forms
3. Have conversations—family members will be relieved
4. Complete the forms—be sure a copy is put on your medical record
5. Review and update the forms periodically—your condition will change

Create a Frame for Your Story

This is your story, your journey, your life…*the illness is just a small part of who you are.*

Your healthcare provider brings medical expertise and can make recommendations. He or she is the artist painting the picture of this medical experience that will fit within the frame you have provided.

Benefits of Advance Care Planning

- You continue to have a say in your medical care, even if you become too sick to speak for yourself.
- You have peace of mind, knowing that you are more likely to receive the medical treatment you would want, and to not receive the treatment you would not want.
- Your family and friends are relieved of the burden of having to make decisions without knowing your preferences.
- You are more likely to have open conversations with your doctors about future treatments; evidence shows better care follows as patients transition to comfort care.
- Studies show advance care planning improves individual and family satisfaction with care, reduces avoidable hospitalizations and transfers between health care settings, and reduces stress, anxiety and depression in surviving relatives.

Role of the Facilitator

- Helps patient's identify questions to ask providers
- Explores the patient's story to gain insight into values, goals, and beliefs
- Assists patient's with defining preferences
- Provides written notes to the provider and other team members

A facilitated conversation lasts about 1 ½ hours.

Fundamental Areas to Discuss

1. What does a good day look like for you?
2. What is your understanding of your health or condition? What do you know about the state of your health?
3. What are your goals & priorities if your health worsens?
4. What are your fears or worries for the future?
5. What trade-offs are you willing to make and unwilling to make? What is most important to you, quality of life or quantify of days?
6. What outcomes are unacceptable to you?

On a good day, what are you doing and who are you with?

What are your wishes for physical, emotional or spiritual comfort?

- Be kept comfortable and minimize pain?
  - Even if the medication impairs your thinking?
  - Even if the medication might alter your breathing and shorten your life?
- Preserve life regardless of your physical or mental health?
- Make health care decisions with consideration for your religion and beliefs?

What are your wishes related to life support?

- If there is no reasonable chance to regain your life physically or mentally?
- If you have physical limitations but can relate to family and friends?
- If you cannot relate to family and friends?
- If you have brain damage or are in a coma?
- If you have confusion or dementia that will not improve?

What are your wishes about how to live?

Want to be healthy enough to care for yourself?

Want to remain in your own home?

Want to live without being dependent upon medical treatments to be kept alive?

Want to die naturally without lingering?

Want health care even if it exhausts personal finances?

Decisions that your loved ones may have to make

CPR-Cardiopulmonary Resuscitation

Artificial Breathing – Ventilator

Artificial Food and Fluids (feeding tubes)

Kidney Dialysis

Tissue and Organ Donation

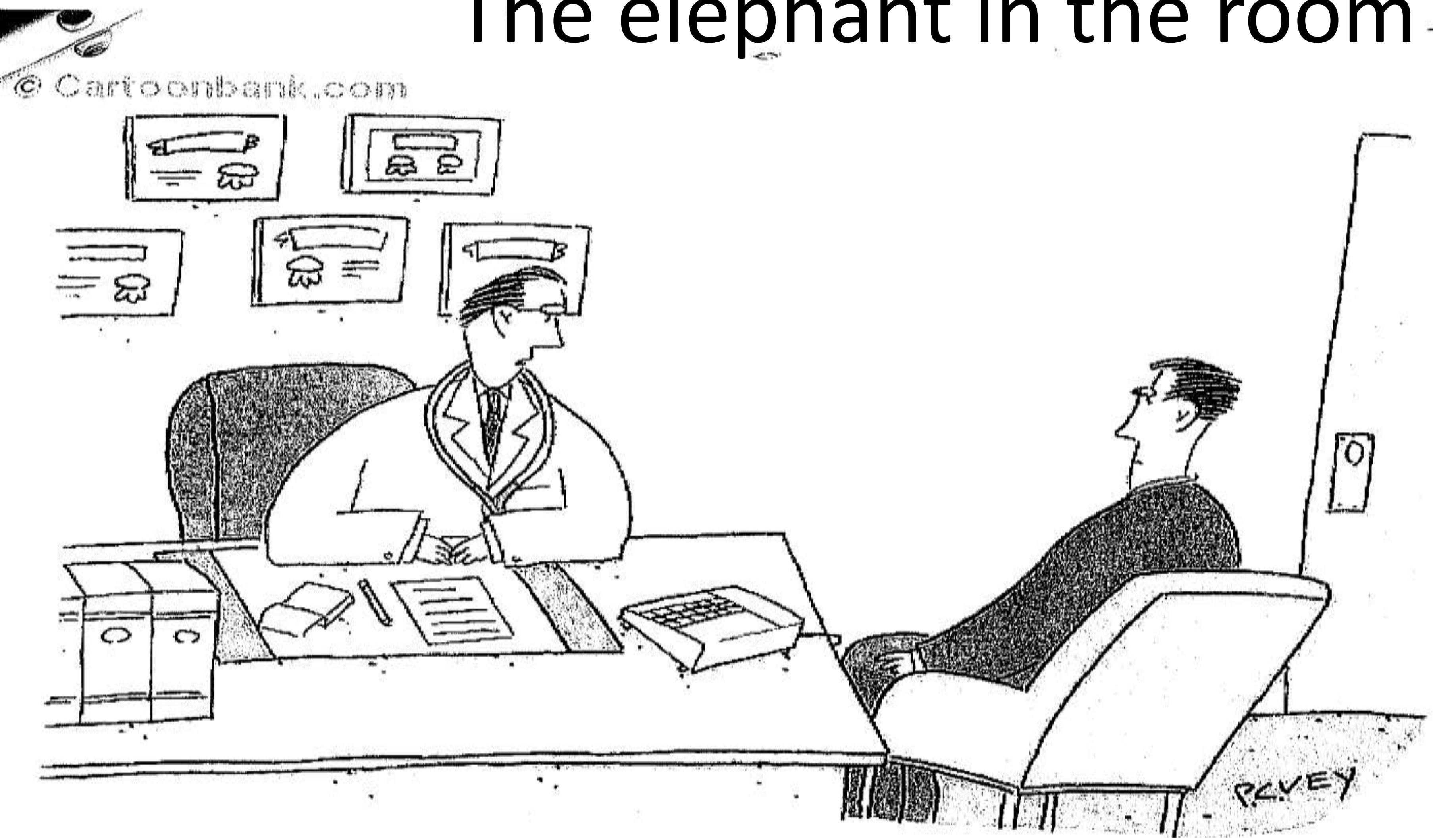
It's less stressful to think about these treatments ahead of time.

You will also want to think about the point at which you might want to transition to comfort care.

- The medical model is based on cure and recovery.
- When patients are not told cure is no longer possible, they are often admitted to ICU and provided more aggressive care than they desire.

Jackson et al, 2012

The elephant in the room …



"There's no easy way I can tell you this, so I'm sending you to someone who can."

Palliative Care and Hospice Foster Hope

Palliative Care is a method of providing comfort care, the goal is to prevent or treat symptoms and side effects of a disease; it should be a part of the picture from the first day a serious illness is diagnosed.

Hospice is a level of comfort care provided to patients who are terminal or whose death is anticipated within six months.

The focus is on symptom management, a peaceful death, & life after death. **Factors** to be considered include the patient's physical condition, symptom management, caring relationships, and faith. As the condition declines hope shifts from time to the meaning of life events with family & friends. Pain and symptoms are managed to conserve energy so the patient can invest time in family, friends and other activities that are important to them.

Donate Life

- **EVERYONE** has the potential to be an organ & tissue donor.
- All major religions consider this a generous act of caring.
- There is no cost to the family.
- One donor can save up to 60 lives.
- Tell your family of your decision so they honor it.
- Recovery is done surgically, viewing is not affected.
- Register at www.life-source.org or on the driver’s license.

Role of the Patient

***Talk with your health care team**: Ask questions if you don't understand.*

***Get support**: Bring a family member to take notes or to help make decisions.*

***Learn more**: If you've done research, bring copies & ask your care team how these findings apply to you.*

Identify cultural or religious beliefs that might affect decisions.

Consider treatment decisions.

Choose an agent.

Be willing to participate in discussions with providers and family members.

Put preferences in writing within a healthcare directive.

Take Time to Reflect

- *These are questions you need to think about and talk about.*
- *These may not be easy questions to discuss and answer.*
- *It takes time to have honest discussion with those you love, to do personal reflection and to define your preferences for care and treatment.*

What aspects of your life give it the most meaning?

Talking About Your Decisions

Valuable opportunity to reflect on what's important with loved ones

Discussion needs to happen *before a crisis*

Can provide comfort to your loved ones

Is up to YOU to initiate

Meal time can be a good time to begin this conversation with your family members.

Role of the Clinician

- Refer patients to facilitators
- Individualize care based on the patient’s goals, values, preferences, & resources
- Follow best practices based on current evidence
- Work as part of a team to best meet the patient’s needs
- Coordinate care across settings
- Assess the resources and environments in which the patient will receive care
- Include the patient as an active participant in decisions

Review documented preferences as care is delivered.

Role of the Clinician (continued)

Consider preferences while noting patient response to treatment.

Key questions a provider might ask:

- What is your understanding now of where you are at with your illness?
- How much information would you like? (Especially r/t time, trajectory)

Share prognosis

- What are your most important goals?
- What functional abilities are so critical you can't imagine living without them?
- How much are you willing to go through to gain more time?
- How much does your family know about your priorities and wishes?

When an Health Care Directive is present, a Health Care Provider must:

Read the document

Validate the content

Respect and follow patient choices

If unable to follow or carry out care that is consistent with the preferences, must provide for transfer of care to another provider/facility

Role of the Healthcare Agent

Is someone who:
  - You trust
  - Knows you well
  - Is willing to assume the role
  - Will advocate on your behalf
  - Will hear and honor your wishes
  - Can make difficult decisions
  - Is resilient enough to endure disagreement if it arises

Can be anyone over the age of 18

Can be a family member, loved one or close friend

Documenting Your Decisions

Health care directives document healthcare decisions; this document is a tool to help you think through and communicate your preferences

1. Gives instructions about aspects of health care including treatments you do or do not want to receive
2. Designates an agent to speak on your behalf when you are unable to speak for yourself

Important to Know

- This is not just an issue for the aging
- Your health care directive should reflect *your* wishes—only you can write your directive
- Lawyers are ***not*** needed
- Make sure your documents are *legally valid* -a notary *or two* witnesses must sign in ND & MN
- A Health Care Directive does not expire and can be updated as needed—review it periodically

What to Do with the Written Document

Give a copy to:

- Your Healthcare Agent
- Primary provider (doctor)
- Health Care Facility
- Close family members
- Others to consider:
  - Faith community leader
  - Attorney

Keep a copy:

- Where you live
- To bring with you if you travel
  - Most states have reciprocity statutes that recognize health care directives completed in other states
- For another facility if care is transferred

Just as birth concludes a pregnancy, death concludes life.

In America we fight hard against age,
illness and death.

Images of Death

We often imagine that we will die suddenly… but most people actually experience a slow, progressive loss of body function.

Key Points about
Writing an Health Care Directive:

- Include your loved ones in the decision—this is a gift you can give to your family and loved ones
- Visit with your primary care provider
- Talk with your faith community leader
- **Don't wait** until you are sick to complete this important document
- Make sure it is properly witnessed
- Make copies for family or health care agent
- Know that it can be changed or revoked at any time by you

Circumstances and Preferences Change

Your decisions about future care desired may change as your health status changes. Directives can be revoked or replaced at any time. Review directives when "5 D's" occur:

1. *Decade*
2. *Death*
3. *Divorce*
4. *Diagnosis*
5. *Decline*

Those with chronic or serious life-limiting illnesses should revisit the goals of care at key transition points:

1. At the time of initial diagnosis of serious health conditions
2. When the disease progresses
3. If there is functional decline
4. When the illness is not responsive to current treatments
5. When alternative disease-focused treatments have the potential to cause as much or greater harm than benefit

Communication is Critical

Your decisions matter…

you have choices

- Talk to your loved ones

  "I learned today that my decisions matter. I want to take this opportunity to talk with you about my decisions for healthcare if I am ever in a situation where I can no longer speak for myself."

- Get information that will help you make the best decisions for you then develop a written health care directive
- Encourage others to document their wishes and talk with their loved ones too

Pitfalls and Limitations of Advance Care Planning

- Failure to plan
- No appointed agents &/or agent not involved in the discussion or informed of decisions
- Unclear patient preferences
- Discussion focused too narrowly or start too late
- Communicative patients are not included in discussions
- Failure to read the directive
- Belief that preferences MUST be written

Having a written plan & naming an agent does not guarantee there won't be disagreements amongst family members.

Resources Are Available

The best time to have conversations with your family members and to get your preferences written in an advance directive is prior to hospitalization.

For more information contact your medical provider or go to www.acpnd.org