Advance Care Planning- What's New?

For Great Plains QIN

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Objectives

1. Describe how Serious Illness Messaging affects Advance Care Planning (ACP).
2. Identify three advantages to ACP you can implement.
3. Define two elements of an advance directive/healthcare directive you learned today.

Poll Question: Which of the following are features of serious illness? (choose all that apply)

- High risk of mortality
- Decrease in function
- Decrease in quality of life
- Strain on the caregiver

Serious Illness

Serious Illness

A health condition that carries a high risk of mortality and either negatively impacts a person's daily function or quality of life or excessively strains their caregiver.

(Kelley &Bollens-Lund, 2018)

What Constitutes Quality Care in Serious Illness?

- For Healthcare Teams: providing symptom management and discussing the emotional aspects of the disease

- For Patients: achieving a sense of control, attaining spiritual peace, succeeding in having finance in order, strengthening relationships with loved ones, and believing that their life has meaning

Serious Illness in America: Impact on Aggressive Treatment

- Technology may prolong life (but not restore it)
- Poor understanding of prognosis
- Frailty, chronic illness
- Failure to treat pain and other symptoms
- Increased use of technology
- Exploding healthcare costs
- Lack of control over rising drug/device costs
- Not establishing “what matters” and what “matters most” to the individual

Anguish in Serious Illness

- Patients fear they will be a physical and financial burden
- If “nothing more can be done,” will healthcare providers abandon them?
- How do families and caregivers adjust to role changes?
- Many drain life savings and/or go bankrupt to cover medical costs

- Older adults may be cared for by an aged spouse who is also ill
- Older children caring for a parent may also have acute or chronic illness(es)

Serious Illness Messaging Toolkit (2022)

“Capture public interest, bypass misconceptions, and increase demand for your services with better messaging. In this toolkit, we'll show you easy ways to improve your messaging – or you can use messages we've tested.”

Steal these messages:

- Advance Care Planning
- Hospice Care
- Palliative Care

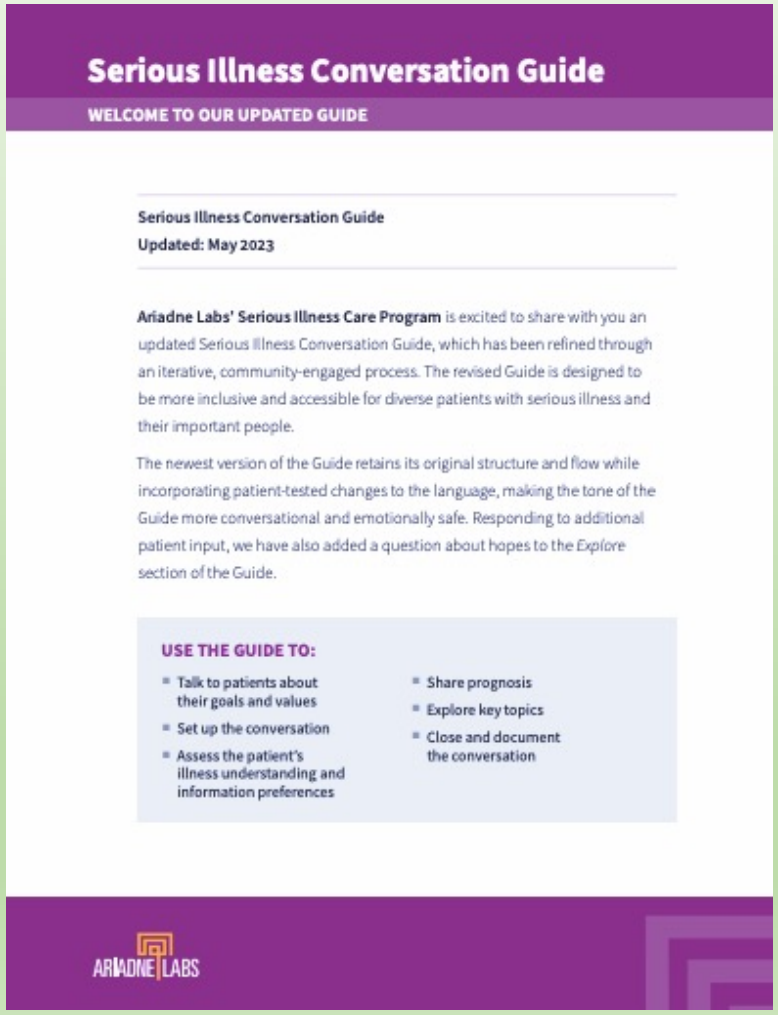
Serious Illness Conversations for Patients and Families

The Conversation Project® is a public initiative to help individuals talking about advance care planning

Institute *for* Healthcare Improvement

the **conversation** project

2023 Serious Illness Conversation Guide



Serious Illness Conversation Guide

WELCOME TO OUR UPDATED GUIDE

Serious Illness Conversation Guide
Updated: May 2023

Ariadne Labs' Serious Illness Care Program is excited to share with you an updated Serious Illness Conversation Guide, which has been refined through an iterative, community-engaged process. The revised Guide is designed to be more inclusive and accessible for diverse patients with serious illness and their important people.

The newest version of the Guide retains its original structure and flow while incorporating patient-tested changes to the language, making the tone of the Guide more conversational and emotionally safe. Responding to additional patient input, we have also added a question about hopes to the *Explore* section of the Guide.

USE THE GUIDE TO:

- Talk to patients about their goals and values
- Set up the conversation
- Assess the patient's illness understanding and information preferences
- Share prognosis
- Explore key topics
- Close and document the conversation

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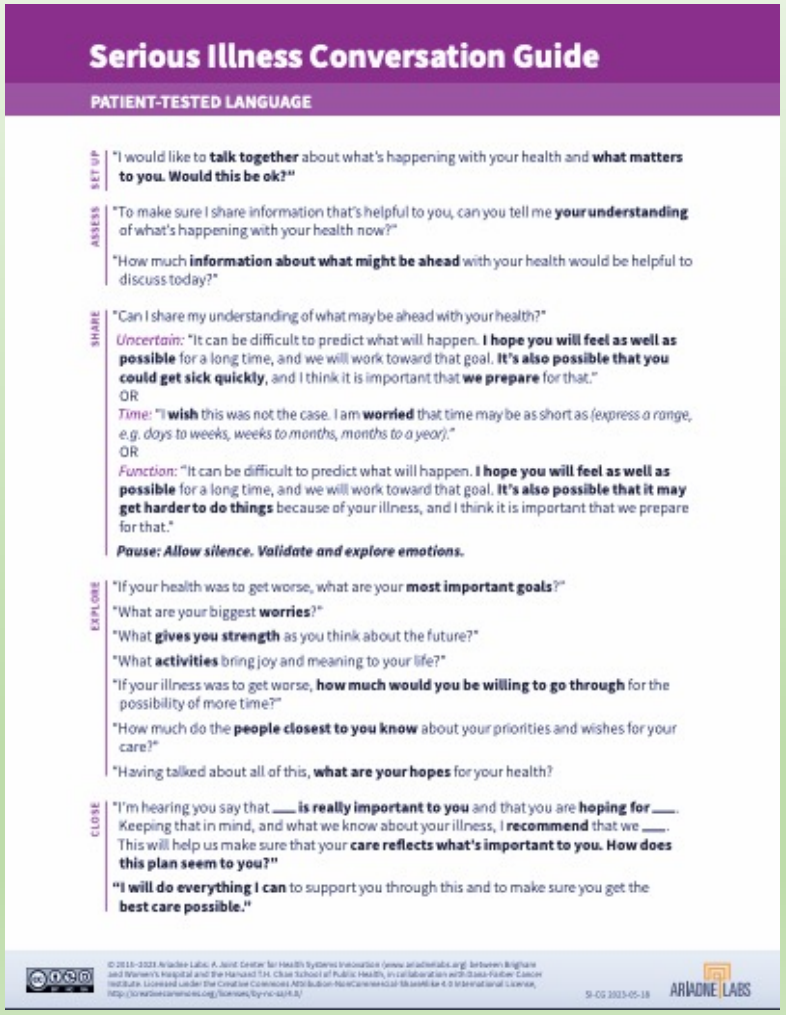

Serious Illness Conversation Guide

PATIENT-TESTED LANGUAGE

SET UP

"I would like to **talk together** about what's happening with your health and **what matters to you. Would this be ok?"**

ASSESS

"To make sure I share information that's helpful to you, can you tell me **your understanding** of what's happening with your health now?"

"How much **information about what might be ahead** with your health would be helpful to discuss today?"

SHARE

"Can I share my understanding of what may be ahead with your health?"

Uncertain: "It can be difficult to predict what will happen. **I hope you will feel as well as possible** for a long time, and we will work toward that goal. **It's also possible that you could get sick quickly**, and I think it is important that **we prepare** for that."
OR
Time: "I **wish** this was not the case. I am **worried** that time may be as short as *(express a range, e.g. days to weeks, weeks to months, months to a year)*."
OR
Function: "It can be difficult to predict what will happen. **I hope you will feel as well as possible** for a long time, and we will work toward that goal. **It's also possible that it may get harder to do things** because of your illness, and I think it is important that we prepare for that."

Pause: Allow silence. Validate and explore emotions.

EXPLORE

"If your health was to get worse, what are your **most important goals**?"

"What are your biggest **worries**?"

"What **gives you strength** as you think about the future?"

"What **activities** bring joy and meaning to your life?"

"If your illness was to get worse, **how much would you be willing to go through** for the possibility of more time?"

"How much do the **people closest to you know** about your priorities and wishes for your care?"

"Having talked about all of this, **what are your hopes** for your health?

CLOSE

"I'm hearing you say that ___ **is really important to you** and that you are **hoping for** ___. Keeping that in mind, and what we know about your illness, I **recommend** that we ___. This will help us make sure that your **care reflects what's important to you. How does this plan seem to you?"**

"I will do everything I can to support you through this and to make sure you get the **best care possible."**

SI-CG 2023-05-18

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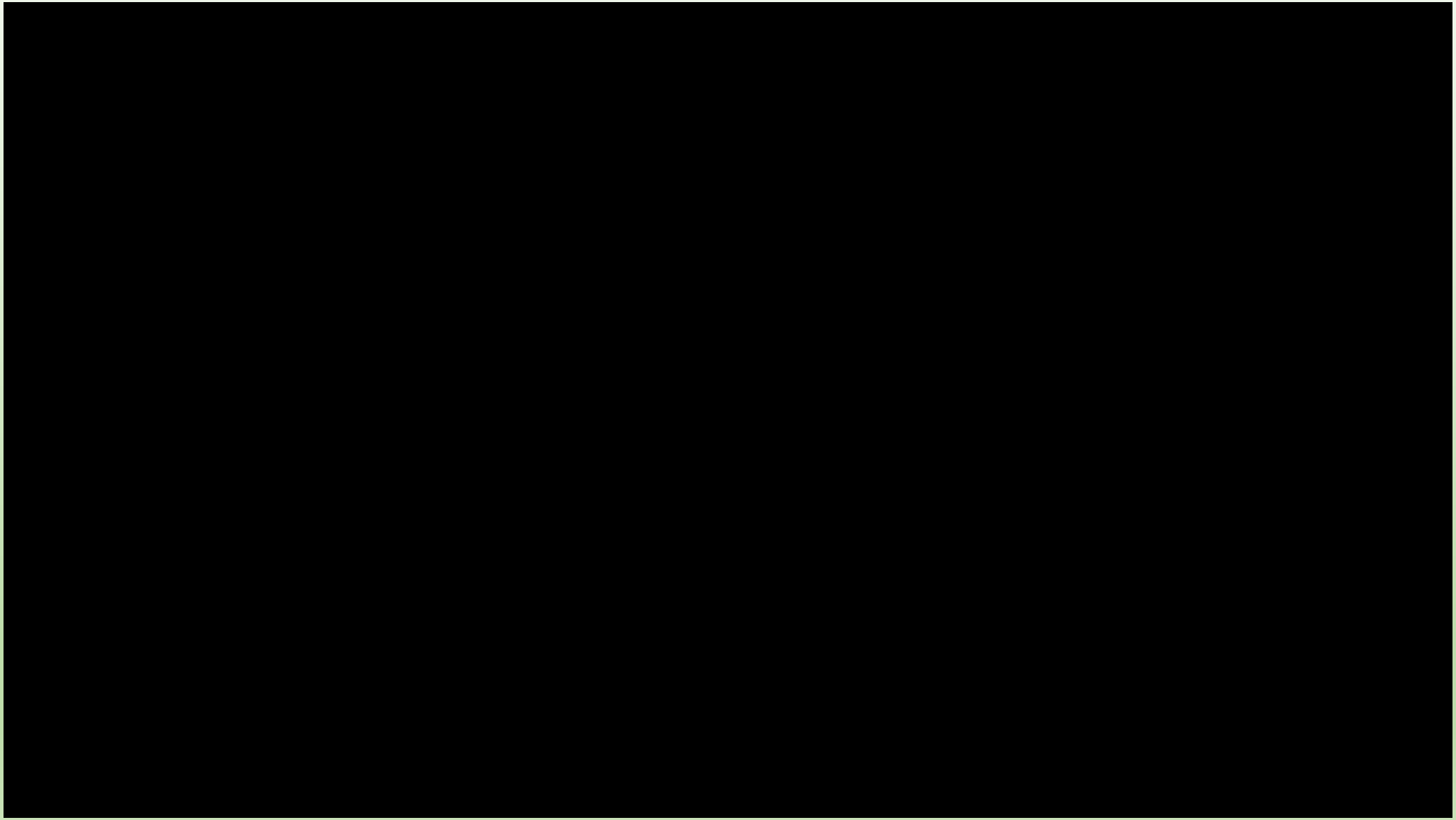
(Ariadne Labs, 2023)

Advance Care Planning

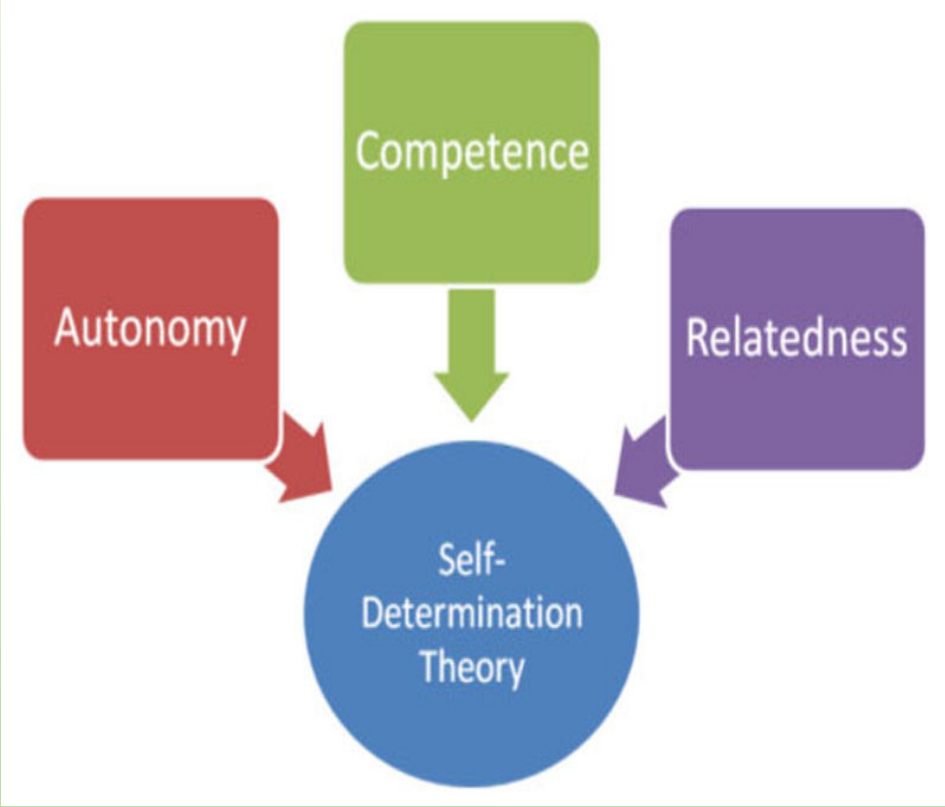
Imagine video



Advance Care Planning: *Definition*

"Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness."
(Sudore et al, 2017)

H.R.4449 - Patient Self-Determination Act (PDSA) of 1990



- All Medicare-participating healthcare facilities must inquire about and provide information to patients on advance directives
- All facilities must provide community education on advance directives
- All healthcare facilities are required to:
  - Provide information about health care decision-making rights
  - Ask all patients if they have an advance directive
  - Educate their staff and community about advance directives
  - Not discriminate against patients based on their advance directive status

(Congress.gov website)

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

Poll Question: What role do you have in having conversations about future health care?(choose one)

1. Initializing the discussion
2. A majority of the discussion
3. Finalizing with the advance health care directive
4. The entire process
5. No role

Advance Care Planning

- Patients can speak up and have a say in their care.
- Advance care planning puts them in the driver's seat.
- Getting health care often involves choices that impact their lives and wellbeing in different ways.
- Treatments only work if they work for them.
- Talk to the people who matter most about the care you want
- The more you speak up, the better your health care can be

Advance Care Planning-
More than a Form- The Process

- Advance Care Planning
  - Lifelong Process
  - Discussion
    - Patient's understanding- diagnosis, prognosis
    - Patient's values, goals, preferences
    - Patient's options
  - Documentation

    -Healthcare Directives- agent, living will

    -Code Level – inpatient/ out of hospital

    -POLST: toolkit www.polst.org/toolkit

Benefits of Advance Care Planning

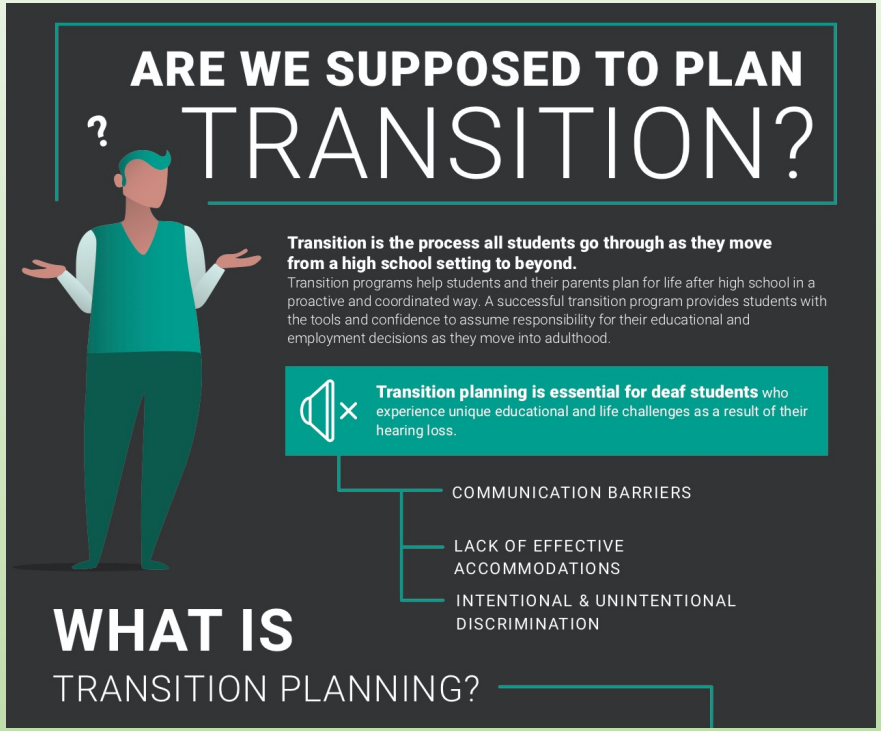
- Gift to the Family
- Gift to the Healthcare Team
- Promotes patient-centered care
- Helps ensure patients receive the care they want
- Reduces the decisional burden of families
- Enhances patient and family satisfaction
- Positively impacts quality of life and end-of –life care
- Promotes higher completion rates of advance directives
- Improves conversations between patients, families and healthcare team

Why “What Matters” Matters Most?

For older adults	For Health systems	For Everyone (patients, families, caregivers, providers, health systems)
• Variation in “What Matters” Most • Feel more engaged and listened to • Avoids unwanted treatment while receiving wanted treatment • Comfort care Always, not just Only	• Better patient experience scores & retention • Avoids unnecessary utilization	• Everyone is on the same page • Improved relationships • It is the basis of everything else

Centering Treatment on Patient's Needs and Preferences- "What Matters"

- Results of Patient Family Questions
- Serious Illness Conversation Guide
- Health Literacy
- As a healthcare consumer
- Documentation/Communication across services / disciplines
- Coordination and transition services



Where Are We Now?

- Advance directive (AD) completion rate in the United States is estimated to be between 18% and 36%
- Less than 50% of severely or terminally ill patients have a completed AD
- Up to 70% of adults who are 60 years old or older lack the capacity to make their own medical decisions in the final days of lie
- Less than 20% of patients have discussed their preferences with their doctor
- By 2030, it is estimated that 72 million Americans will be 65 years or older, by which chronic conditions and/or functional limitations will become more prevalent

Communication Needs of the Patient/Resident/Client

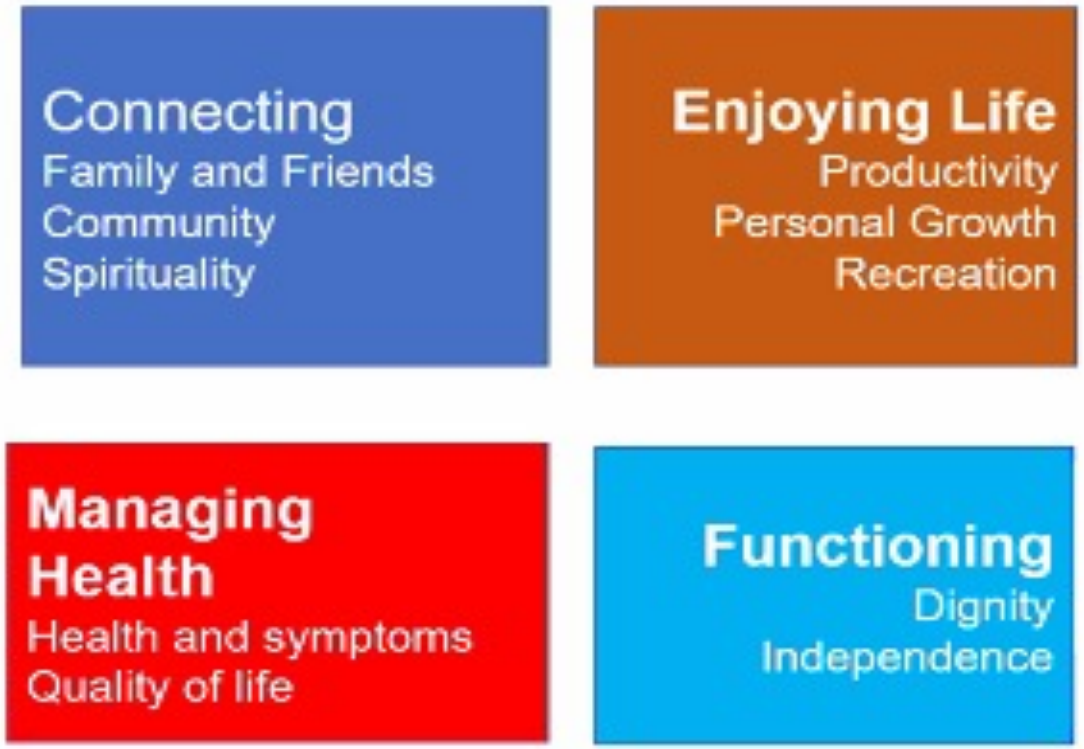
- Information for informed choices

“ I don't know what I don't know:

- Simplify information
- Disclosure of feelings
- Verbalization of fears
- Sense of control
- Discussion about the meaning of life
- Maintaining hope
- Reassurance of pain and symptom management

Patient Priorities Care Model

- What makes today a good day?
- Who are the most important people in your life? What do you like to do together?
- What is most important to you about taking care of yourself?
- What do you hope your healthcare can do for you?



https://patientprioritiescare.org/

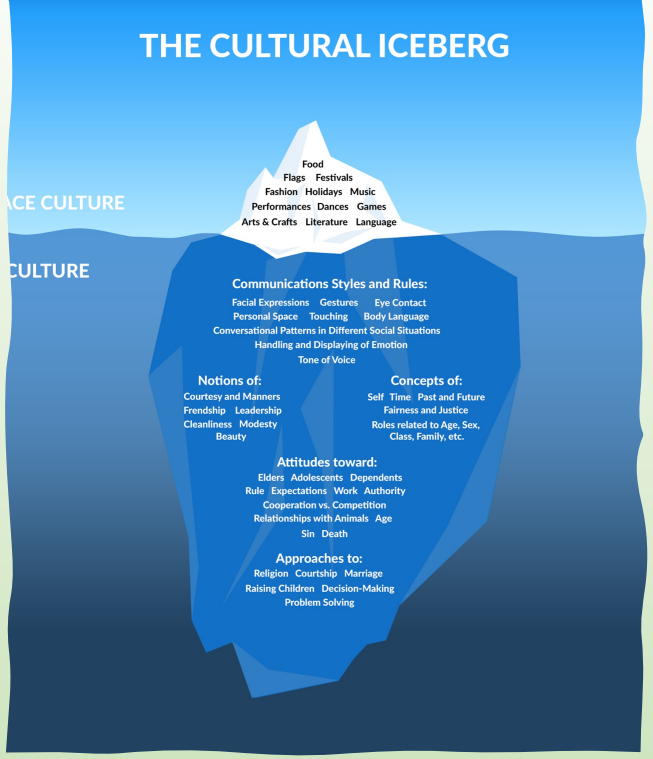
How Can We Improve?

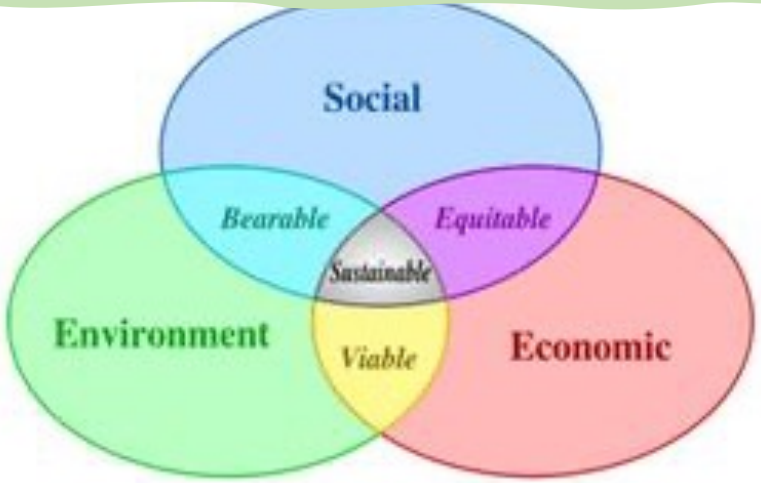
- Better understand disease trajectories to provide patient-centered care and prepare family members for end-of-life (EOL) care
- Integrate ACP as part of our practice and normalize ACP with our patients, their families, and the community
- Encourage patients to complete and disseminate an advance directive (AD) prior to a healthcare crisis from occurring. If a patient attempts to complete an at that time, it is no longer an advance directive, but a crisis directive

(Miller, 2017)

Why Are ACP Discussions **Not** Started?

- Lack of experience, tools and skills
- Hard, difficult topic
- There isn't time
- It's not the right time- "It's too early!"
- The right person
- The more a provider/healthcare professional prepares for discussions and practices, the more skilled that provider becomes





If You Don't Ask- You Won't Know

Assess vs Assume:

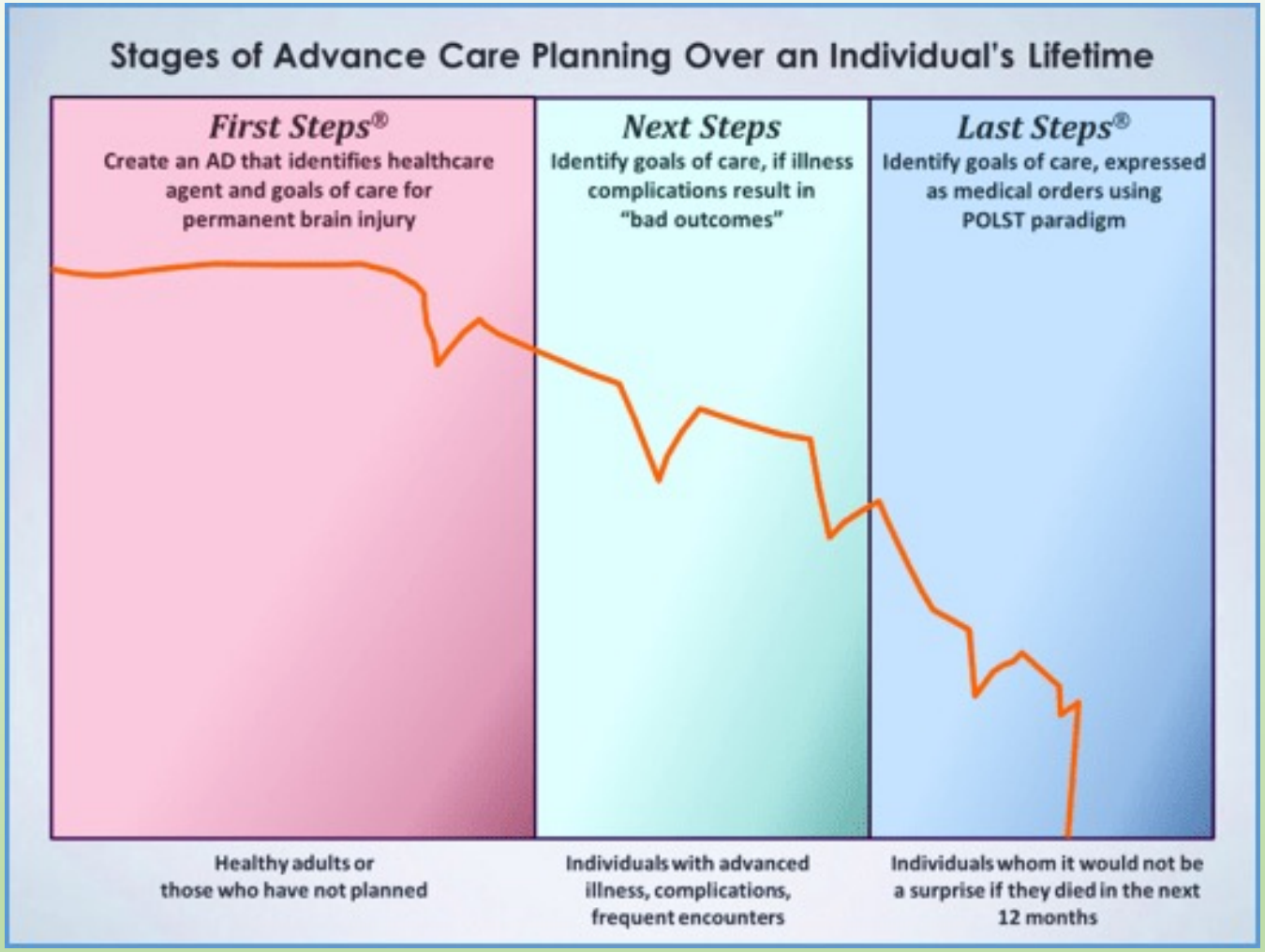
- Social determinants of health
- Culture determinants
- Spiritual determinants

Goal:

A sense of belonging and interconnectedness

Communication Across the Illness Trajectories

- Continue to build trust and open communication
- Be present – good listener
- Discuss their understanding of diagnosis prognosis, treatment options, benefits, burdens, and expected outcomes
- Maintain the connection
- Explore goals of care
- Share community resources
- Support friends and colleagues
- Avoid giving personal opinions-use generalizations
- Be open to discuss plan A, B, C



(Decide to be Heard, 2021)

When to Begin Advance Care Planning (ACP)

- According to the Institute of Medicine (2015), “All individuals, including children with the capacity to do so, have the opportunity to participate actively in their health care decision making throughout their lives and as they approach death, and receive medical and related social services consistent with their values, goals, and informed preferences” (p. 12)
- Any adult, age 18 years and older, can complete an advance directive
- Address ACP at milestones:
  - Turning 18
  - Leaving home to go to college
  - Enlisting in military
  - Marriage
- Advance care planning is not an aging issue – it is a public health issue

How to Begin the Conversation

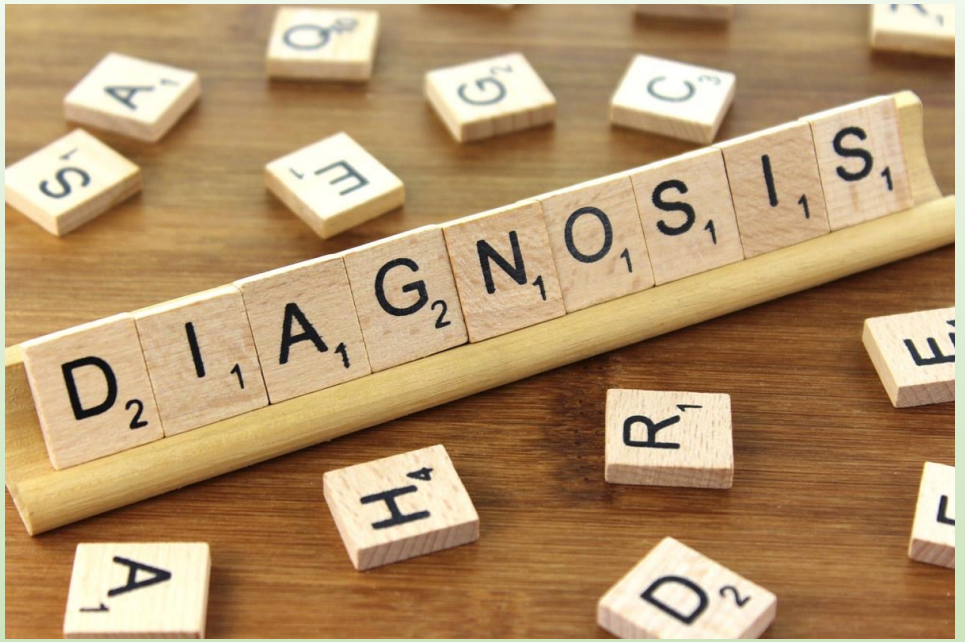
- Initiating a discussion that may lead to advance care planning:
- Ice Breakers
- Family background/personal background
- Questions to ask
  - What do you understand about your prognosis?
  - What are your biggest concerns/fears?
  - How do you want to spend your time (goals)?
  - What kind of tradeoffs are you willing to make?
  - Who should make decisions for you if you are unable?

Patient/Family Questions to Ask

- Do I have a serious or life-limiting illness?
- Can my illness be cured?
- If my illness can't be cured, are there treatments that can slow down my illness?
- What kind of care is available to focus on making me comfortable?
- If my illness keeps getting worse, when is it a good time to think about getting supportive and comfort focused care?
- Will you be the one to tell me when to contact hospice?
- Will you stay involved with my care even when I am no longer looking for treatment for my disease?

Five Questions to Ask at Diagnosis

Can you tell me that again?	**Can I say that back to you, so I know that I understand what you are telling me?**
What do we do next?	**How serious is this?**
What else should I be asking at this point?	**(GetPalliativeCare.org website)**



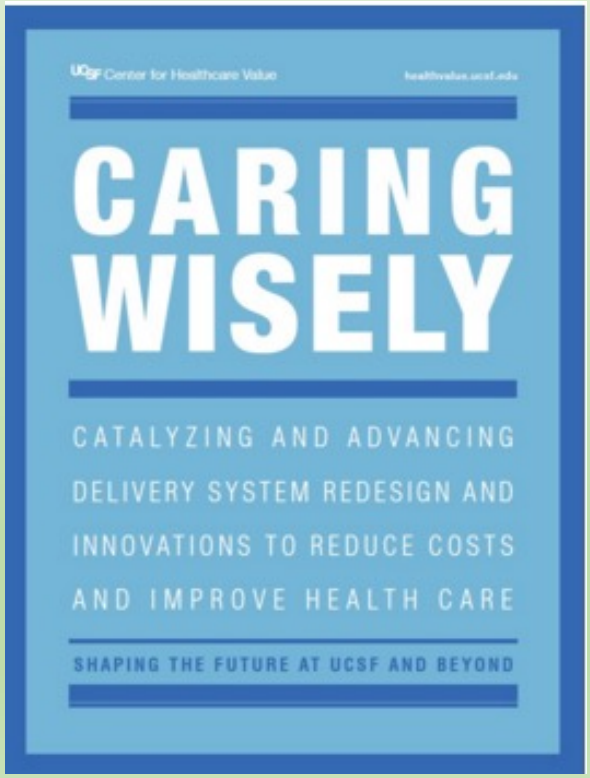
Four Crucial Questions To Ask Your Doctor- As a Consumer/Customer/Client

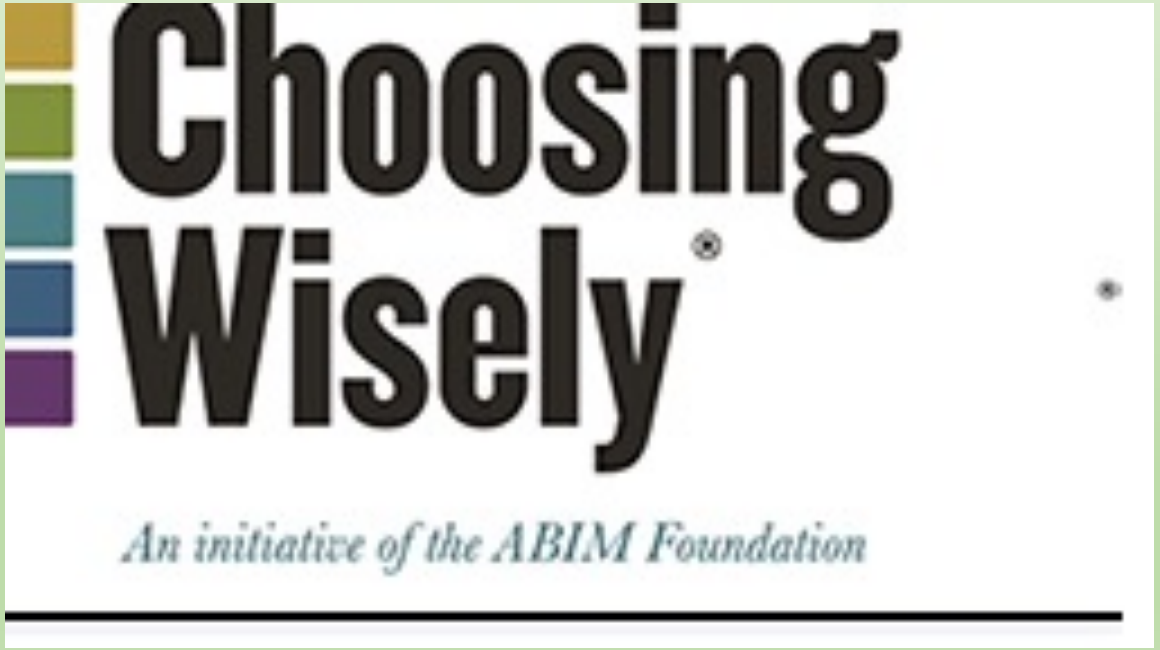
1. **What are the odds this test/medicine will benefit me?**
2. **What are the downsides or harms of the test/medicine?**
3. **Are there simpler safer alternatives options?**
4. **What happens if I do nothing?**

(Mandrola, 2017)

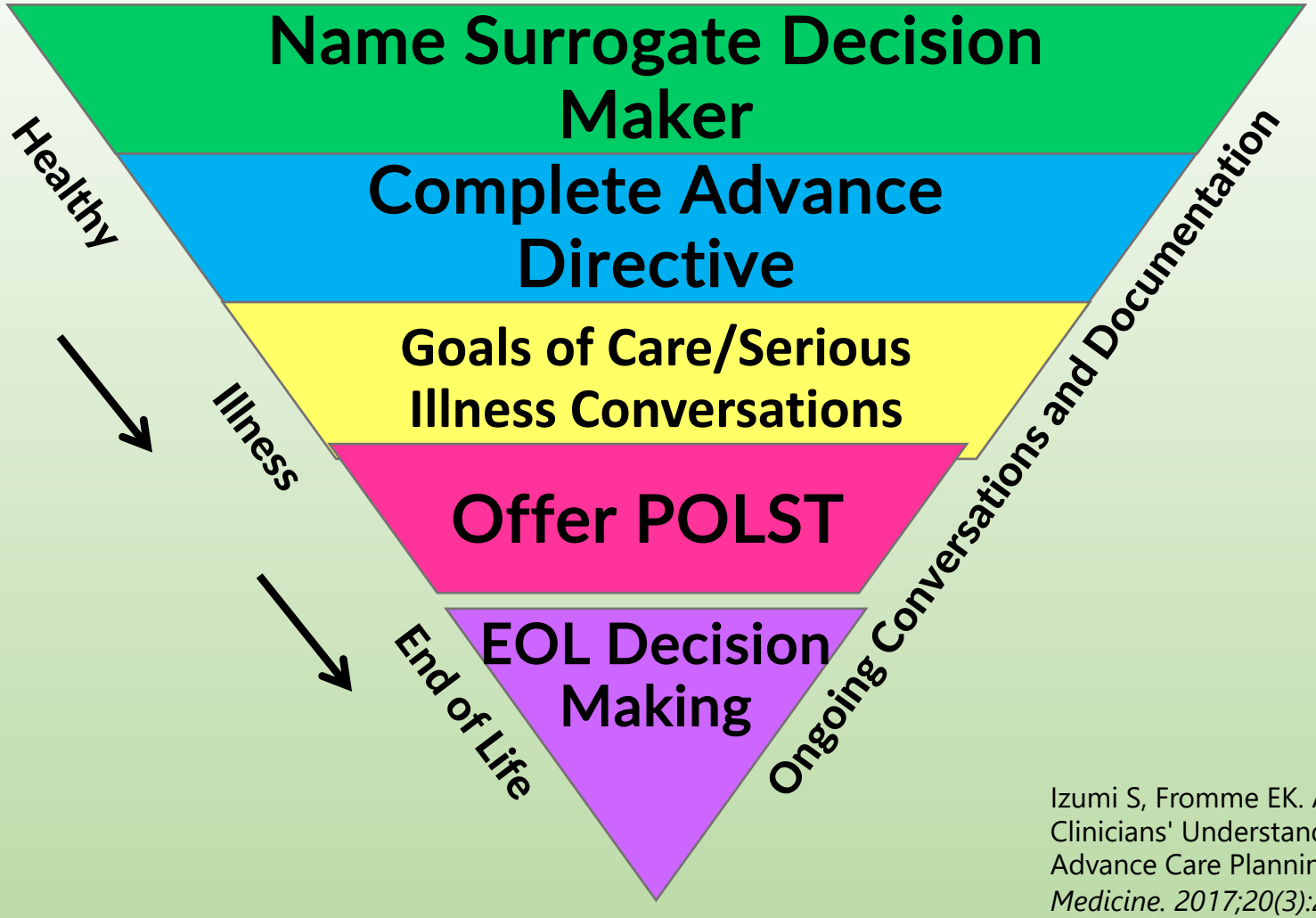
Giving Choices

- Aggressive Treatment
- Time-Limited, goals
- Comfort focus including hospice from the beginning?
- Life sustaining treatment





Aint the Way to Die- ZDogg, MD



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Continuum of Advance Care Planning

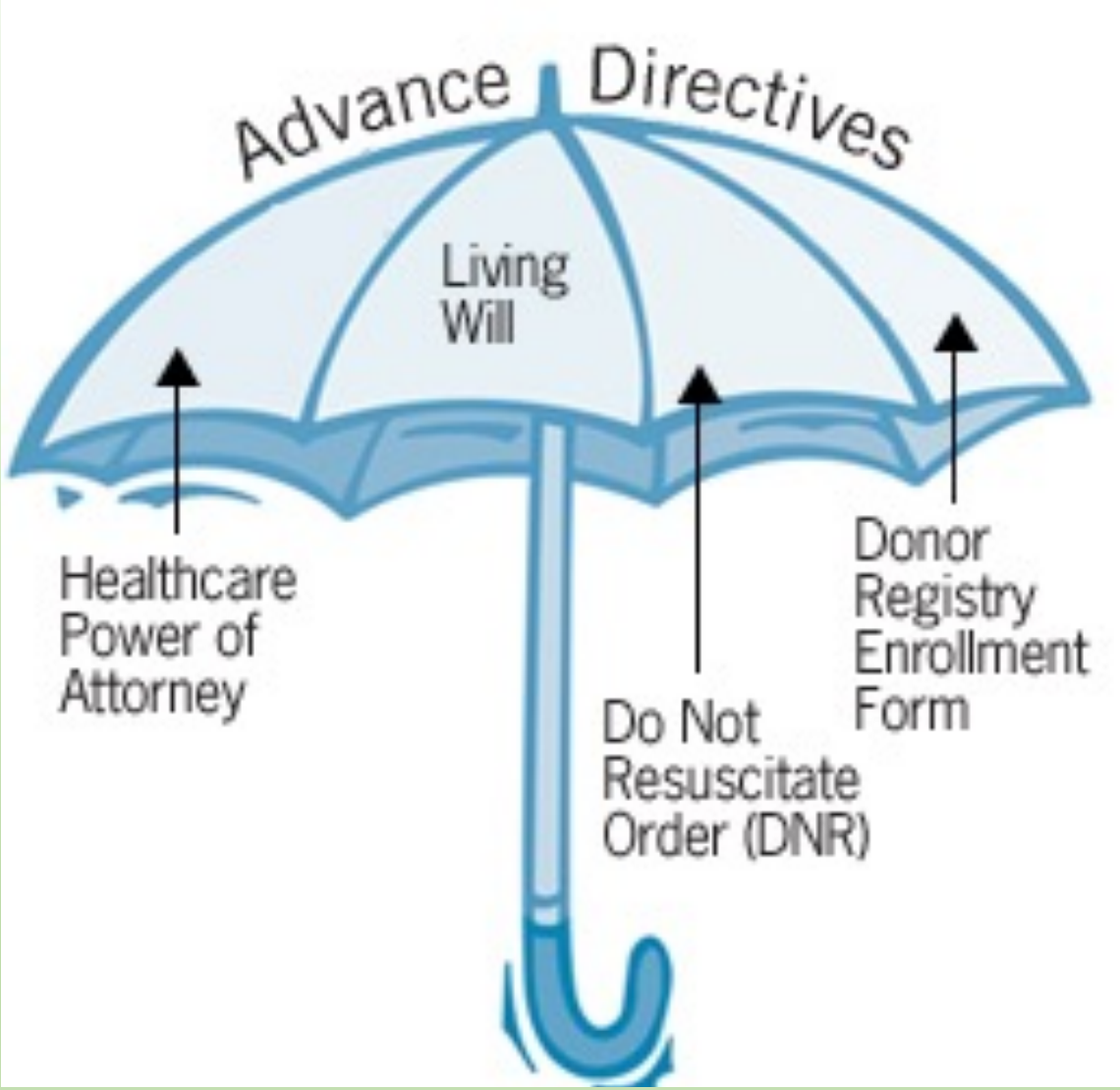
Advance Directives

Health Care Directives

What is an Advance Directive?

“Legal documents that specify the type of medical care a person wants to receive once he or she can no longer make such decisions, and who should be in charge of making them.”

(Alzheimer’s Association)



Who Needs a Healthcare Directive?

Every Adult over 18

Living Will or Financial Will?

Health Care Directive (HCD)/ Advance Directive (AD)

A written document that is used to express preferences guiding future medical decision-making **and/or** appointment a healthcare agent
May or may not include the healthcare agent

Living Will

A written statement about the kinds of medical care wanted to receive under specific conditions

The" Will"/ Living Trust

Financial documents that to distribute financial assets and properties after death
Estate planning
"Personal Will and Testament"

Advance Directives and Living Wills are often used interchangeably

North Dakota Century Code Chapter 23-06.5

ND Health Care Directives

South Dakota Administrative Rule

44:76:13:10. Advance Directive.

Different Names for Advance Directives

Health Care Directive (North Dakota Century Code)

Living Will

Personal Directive

Medical Directive

Advance Decision

Mental Health Advance Directive

Enduring Power of Attorney

Advance Directives and Legal Capacity (Alzheimer's Association)

A person with dementia has the legal right to limit, refuse or stop medical treatments.

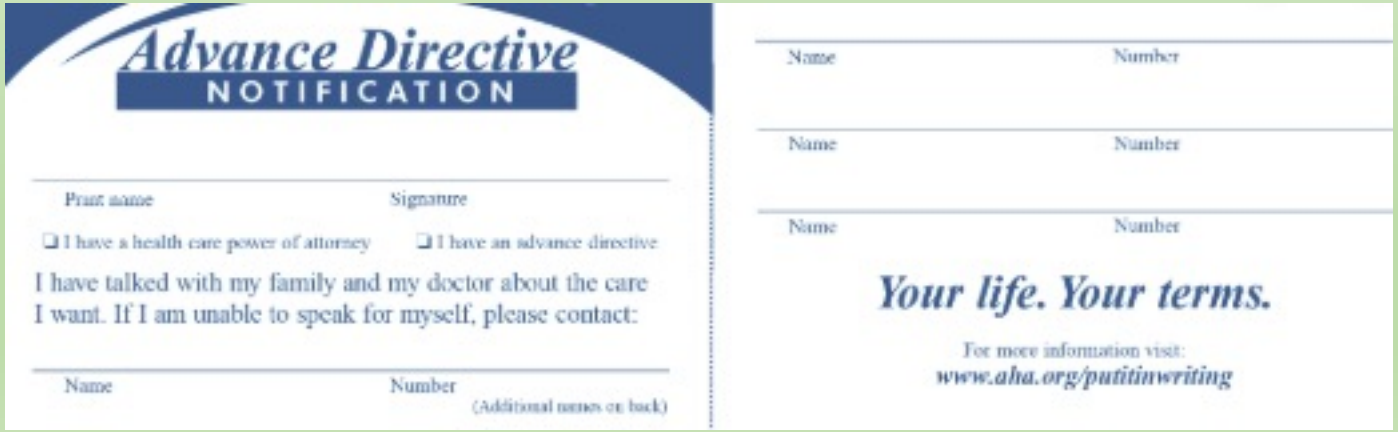
Advance directives should be made when the person with dementia still has legal capacity.

Only the individual can complete an Advance Directive.

If advance directives are not in place, the family must be prepared to make decisions consistent with what they believe the person would have wanted, while acting in that person's best interest.

Completing the Healthcare Directive

- Practice one first
- Discuss with your agent
- Before Signing -witness required (notary, 2 witnesses)



Advance Directive
NOTIFICATION

Print name Signature

❑ I have a health care power of attorney ❑ I have an advance directive

I have talked with my family and my doctor about the care I want. If I am unable to speak for myself, please contact:

Name Number
(Additional names on back)

Name Number

Name Number

Name Number

Your life. Your terms.

For more information visit:
www.aha.org/putitinwriting

When to Review Health Care Directives

The American Bar Association encourage clients (patients) to revisit their advance directives and legal documents whenever any of the ”six Ds” occur:

- You reach a new **DECADE** in age;
- You experience the **DEATH** of a loved one;
- You experience a **DIVORCE**;
- You receive a **DIAGNOSIS** of a significant health condition;
- You experience a significant **DECLINE** in your functional condition; and
- You change your **DOMICILE** or someone moves in with you

(Sabatino & Arkfeld, 2019, p. 56))

What to Do with the Health Care Directive?

Tell primary and alternate Health Care Agents and make sure they feel able to do this important job fo in the future. In ND, Healthcare Power of Attorney signature require/accept this appointment.

Talk to the rest of my family and close friends who might be involved if I have a serious illness or injury, making sure they know who my Health Care Agent is, and what my wishes are.

Give my primary and alternate Health Care Agents a copy of this document.

Who Else Should Get Copies?

Give a copy of this completed document to PCP and other health care providers, make sure they read, understand and will follow wishes.

Keep a copy of this document where it can be easily found (pill list, glove compartment).

Take a copy of this document any time admitted to a health care facility and ask that it be placed in the medical record.

Consider keeping a copy on a jump drive.

Have an electronic copy loaded onto the ND Health Information Network.

Honoring Choices® North Dakota
(Soon to be Advance Care Planning of North Dakota)

Vision: The health care choices a person makes become the health care the person receives

Goal: To assist communities to develop a successful advance care planning process.

Honoring Choices®
NORTH DAKOTA

ND HIN Registry for Advance Directives and POLST

Health Care Directive Registry- https://www.ndhin.nd.gov/services-0/nd-health-care-directive-registry

What is the ND Health Care Directive Registry?

A registry that was developed by the North Dakota Health Information Network (NDHIN) for ND citizens to securely store and share their health care directives. The registry is a self-service tool allowing you complete control over your health care directives.

What types of health care records can be saved in the registry?

- Health Care Advance Directive
- POLST (Physician Orders for Life Sustaining Treatment)

NORTH Dakota | Health Information Network
Be Legendary. INFORMATION TECHNOLOGY

SD Advance Directives and Medical Orders

https://doh.sd.gov/health-care-professionals/ems-trauma-program/advance-directives-and-medical-orders/

Comfort One Bracelet

The Comfort One bracelet costs $44.70, is optional, and can be used for identification in place of the Comfort One form. This is a great option for those away from home as an alternative to carrying the Comfort One EMS Cardiopulmonary Resuscitation Directive.

comfort ONE

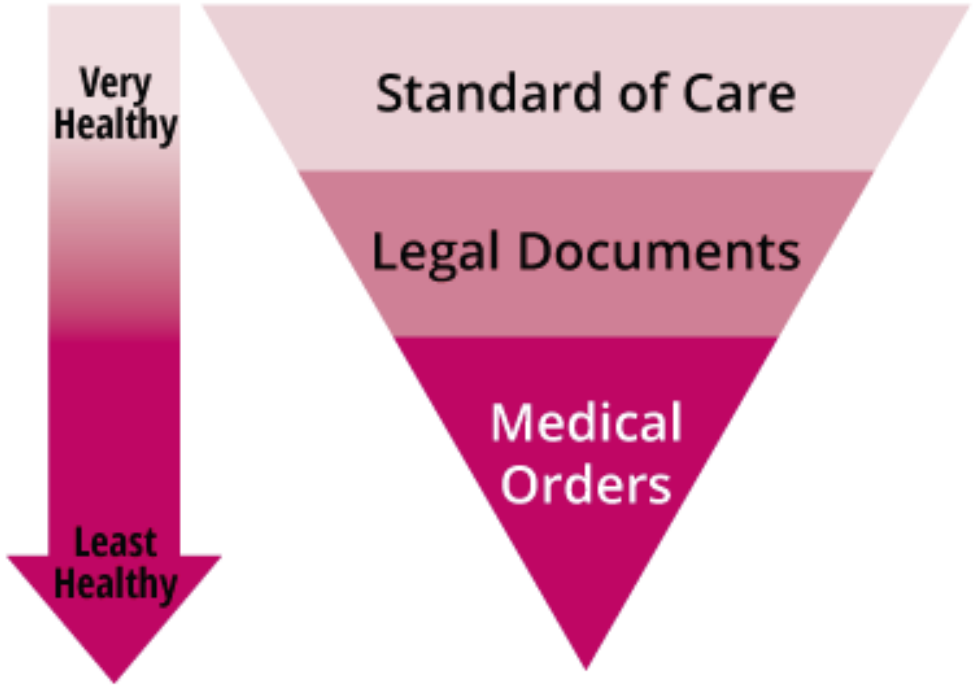
LifeCircle SOUTH DAKOTA
Partners Improving End of Life Care

POLL Question: **Were you aware of** the ND Registry and SD Comfort One Bracelet?

1. Yes (I knew about both)
2. Partially (only in my state)
3. No

The Default Policy

It is very important that individuals understand that it is healthcare policy is always to provide all life sustaining treatments for any person that has not told healthcare professionals that there are treatments that they do not want."



Standard of Care is the treatment automatically provided when you can't communicate. Providers will do all they can to save your life.

Legal Documents. You use these to authorize someone to make health care decisions for you. You also include your general treatment wishes in these.

Medical Orders (POLST forms and do not resuscitate orders) are created and signed by health care providers and give specific medical treatment orders to other providers based on your wishes.

https://polst.org/advance-care-plans/

Medical Record Documentation

POLL Question: Do you know where to look for the Health Care Directive and POLST/MOST in your agency's medical record?

1. Yes
2. No

Where to Look in the Medical Record

- Does it have separate section/tab?
- Is it consistent with the Code Status?
- Does it reflect the person's wishes?
- Do all health care professionals know those wishes?


abcnews.com/worldnews

For More Information

Contact

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