



Advance Care Planning: *It's About the Conversation*

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Objectives

- Define advance care planning (ACP)
- Describe Honoring Choices Wisconsin
- Define three ACP decisions
- Provide tools for “being the difference” in ACP

What is advance care planning?

- A. A document
- B. A process
- C. Only for very sick people

Advance Care Planning is:

A person-centered process of ...

- **Understanding**
- **Reflecting on**
- **Discussing**

... future medical decisions,
including end-of-life preferences.



Advance Care Planning is:

- **Planning ahead** for future health care decisions
- If a **sudden, unexpected event** (like a car accident or sudden illness)
- Left you **unable to communicate** and make your own health care decisions
- And **others would need to make decisions** for you.

Why is ACP important?



World Death Rate Holding Steady At 100 Percent

[News](#) • [survival](#) • [ISSUE 31•02](#) • Jan 22, 1997

GENEVA, SWITZERLAND—World Health Organization officials expressed disappointment Monday at the group's finding that, despite the enormous efforts of doctors, rescue workers and other medical professionals worldwide, the global death rate remains constant at 100 percent. . . .



Why is ACP important?

The care you receive may not reflect your values.



Health care providers may not know your treatment preferences.



Your family may question whether they made the right decisions.



The Facts



70% of people say they prefer to die at home.

70% die in a hospital, nursing home, or long-term-care facility.

Centers for Disease Control and Prevention (2005)

The Facts

60% of people say making sure their family is not burdened by tough decisions is "extremely important."

56% have not shared their end-of-life wishes.

Survey of Californians by the California HealthCare Foundation (2012)



The Facts



80% of people say they would want to talk to their doctor about end-of-life care.

7% have had an end-of-life talk with their doctor.

Survey of Californians by the California HealthCare Foundation (2012)

The Facts

75% of physicians whose patient had an advance directive were not aware that it existed.

Critical Care Journal (2007)





Mission: to promote the benefits of and improve processes for advance care planning across the state, in health care settings and in the community.



Honoring Choices Wisconsin

- Our approach is comprehensive, and based on a few key principles:
 - ✓ Advance care planning is for all adults and is not a one-time event; it's a process over the life course.
 - ✓ It's about the conversation. Legal documents alone cannot take the place of a well-prepared health care agent.
 - ✓ Systems must be created to ensure that advance care planning conversations are routinely offered, scheduled, had and documented in the medical record.

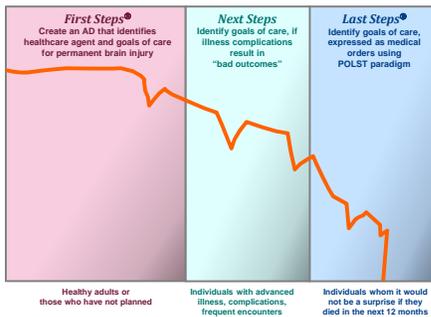
Respecting Choices

Respecting Choices® is an evidence-based advance care planning model developed by Gundersen Health System in La Crosse to meet this desired outcome:

To know and honor an individual's informed plans by:

- Creating an effective planning process, including
 - Selecting a well-prepared healthcare agent, when possible
 - Creating a plan that reflects informed decisions geared to the person's state of health
- Making plans available to treating health professionals
- Assuring plans are incorporated into medical decisions, when needed

Stages of Advance Care Planning Over an Individual's Lifetime



The Standard Approach in the US

- Provide information to adult patients about their legal rights to refuse treatment and to have an advance directive (AD)
- Ask patients if they have an AD at admission
- Encourage the completion of statutory AD documents
- Ask simple questions, such as, "Do you have an AD?" and "If your heart stops, should we do CPR?"

Just completing a statutory Advance Directive DOES NOT WORK

The standard approach to advance directives (ADs) consistently fails to improve care

- The prevalence of ADs is low.
 - General population 20-30%
 - End-stage illness < 50%
- ADs are often unavailable at the place of treatment
 - Available to the physician only 25% of time
- ADs are often not helpful to decision making (i.e., too vague)
- ADs are often not followed
 - Unavailable or ambiguous
 - Not understood/supported by loved ones

(Agency for Healthcare Research and Quality, 2003)
 (National Academy of Sciences, Institute of Medicine, 2014)
 (Rand Corporation, 2007)
 Wilkinson Wen er Shu arman 2007

For ACP to Be Successful...

Plans must be:

- Created — high prevalence is essential
- Specific enough for the clinical situation
- Accurately reflect the individual's preferences
- Understandable to those making decisions
- Available to the decision makers
- Incorporated into decisions, as needed

(Fagerlin & Schneider, 2004)

From Documents to Conversations?

- Culture change; transformative
- Organization and community effort
- Involvement of multiple professionals
- Commitment to learning new skills and practices

Outcomes of Sustained Approach

Increase in:

- Individual and family satisfaction
- Prevalence of planning (including special populations)
- Percentage of plans at time of death
- Number of hospice admissions

Reduction in:

- Family stress, anxiety, and depression
- Number of hospital deaths

Prevalence, Availability, and Consistency of Advance Directives in La Crosse County after the Creation of an ACP System in 1991-1993

	LADS I Data collected in '95/'96 N=540	LADS II Data collected in '07/'08 N=400	P value
Decedents with ADs (%)	459 (85.0)	360 (90.0)	.023
ADs found in the medical record where the person died (%)	437 (95.2)	358 (99.4)	<.001
Treatment decisions found consistent with instructions	98%	99.5%	0.13

(Hammes & Rooney, 1998)
 (Hammes, Rooney, & Gundrum, 2010)



ACP:
 Helping
 Achieve the
 “Quadruple”
 Aim

Improved Patient Experience

- Assists in providing care and treatment that is consistent with individual goals and values
- Results in high individual and family satisfaction
- Increases prevalence of planning in racially, ethnically, and culturally diverse communities

Better Outcomes

- Integrates ACP throughout the community
- Increases hospice use at end of life
- Promotes timely and appropriate referrals for other needed services (care coordination)

Lower Costs

When individual's goals and values are understood and honored, ACP:

- Reduces unwanted care, treatment, and hospitalizations
- Reduces cost of care in last two years of life
- Reduces hospital deaths

Cost of Care in the Last Two Years of Life

Hospital	Inpatient Days per Decedent Last 6 months of life, 2012	Total Medicare Reimbursement of Care/Patient Last 2 Years of Life, 2012
Gundersen Health System	6.6	\$57,191
University of Wisconsin	8.9	\$82,162
Cleveland Clinic	13.6	\$82,744
Mayo Clinic	12.1	\$94,330
UCLA	18.8	\$142,202
New York Univ. Medical Center	16.8	\$135,066
National Average	8.7	\$70,686

Source: Based on 2012 Dartmouth Atlas Study Methodology. The Dartmouth Atlas methodology examines hospital inpatient care for the last two years of a Medicare patient's life.

Improved Clinician Experience

ACP:

- Provides the skills to open the conversation
- Reduces crises and indecision at end-of life
- Is a team approach, not just the clinician's responsibility

The Benefits of ACP Facilitation

- Standardizes the process of planning so that an effective, shared practice exists across an organization or community
- Improves the communication of care plans over time and setting
- Makes it more probable that those close to the patient both know and support the plan created.

Who are ACP Facilitators?

- Typically nurses, chaplains, social workers and volunteers
- Specially trained using Respecting Choices® curriculum
 - 4-6 hour online education
 - 8 hour in-person training focused on skill acquisition
 - Ongoing practice and professional development

Self-Assessment

When talking with an individual about advance care planning, do you:

- A. Listen more than talk?
- B. Use open-ended questions?
- C. Remain value-neutral?
- D. All, none or some of the above?

What does an ACP Facilitator do?

Leads an in-depth conversation with individuals and those closest to them to:

- Choose a decision-maker
- Discuss past experiences
- Define living well
- Identify religious, spiritual, personal or cultural views that would affect treatment choices
- Clarify goals of treatment if there was little chance for recovery
- *After the conversation*, assist with completion of an advance directive

What skills does a Facilitator use?

1. Explore meaning of words and phrases
"What does 'being a burden' mean to you?"
2. Paraphrase/clarify
"You were frustrated being in the hospital; tell me more."
3. Ask, "Anything else?"
"You said you learned from that experience how important it is to have a health care agent. Anything else?"
4. Use the Teach-Back Strategy
"These are new ideas for many people, so I want to make sure I was clear. Can you tell me what you now understand about _____?"
5. Remain value-neutral!

What does every competent adult need to plan for?

We can't predict the future



Three decisions

- 1) **Who you want to be your health care decision-maker (health care agent)**
- 2) **What cultural, religious, spiritual or personal beliefs you have that might impact your decisions**
- 3) **What health care you would want to receive if you have a sudden illness or injury**

How to Begin - #1

- ✓ **Choose a decision-maker (health care agent)**



Health care agent



The person **chosen by a patient** to make health care decisions in the event that the patient cannot make decisions for him/herself.

An agent should be willing to:

- **Accept this role**
- **Talk with you about your goals, values and preferences**
- **Follow your decisions, even if he or she does not agree with them**
- **Make decisions in difficult moments**

How to say it:

- *“I was thinking about what happened to _____, and it made me realize...”*
- *“Even though I’m okay right now, I’m worried that _____, and I want to be prepared.”*
- *“If I get sick in the future and can’t make my own decisions, would you work with my doctors and help make medical decisions for me?”*



The Conversation Project 2013

Honoring Choices Minnesota

It's about the conversation

START THE CONVERSATION THE EASY WAY - WITH A VIDEO EMAIL

Sometimes it's difficult to know how to begin this type of conversation -- maybe even embarrassing. Let one of our videos break the ice for you. Simply fill in your information, your family member or loved one's information, add a note, and pick a video below. Then press send and your loved one will receive an Honoring Choices email with a link to the video.

Your First and Last Name Family Member's First and Last Name

Your E-mail Address Family Member's E-mail Address

Personal Message to Your Family Member

Get Involved! Click here here to learn more

Featured Video

Upcoming Airings

Honoring Choices: Giving Thanks
 Thu Nov 28th, 2013 @ 12:00 am on get link
 Thu Nov 28th, 2013 @ 6:00 am on get link
 Thu Nov 28th, 2013 @ 12:00 pm on get link

Honoring Choices: Health Choices and The Law

SELECT A VIDEO
 Click on a thumbnail to preview our videos



The Best Time (00:00:12)
 Jearlyn Steele says now is the best time to talk to your family.



Humor Your Family (00:00:07)
 Jearlyn Steele says your family wants to have a conversation.



It's Time to Tell (00:00:07)
 Jearlyn Steele says it's time to tell your family what you want.



Too Embarrassed (00:00:13)
 Jearlyn Steele says your family is too embarrassed to talk to you.



Gather the Family (00:00:06)
 Jearlyn Steele says time to gather the family to talk about end of life issues.

The video link you are e-mailing is [Send Email](#)

PREPARE

How to Ask Someone to Be Your Decision Maker

Click the pictures to see the videos.
 Your situation may be different.



James asks Cynthia to make decisions **ONLY IF** he is too sick to make his own

[Click to Play](#)



John asks his son David to make **ALL** of his decisions for him

[Click to Play](#)

Click the **NEXT** button to move

[GO BACK](#)
<https://www.prepareforyourcare.org/>
[NEXT](#)

PREPARE

Do any of these reasons make it hard for you to choose medical decision maker? Click on as many as you want.

[Show Menu](#)

I am afraid to think about being really sick.

I would rather leave my health to God and to prayer.

I do not want to burden my friends and family members.

Or, something else is making this hard to do.

Click the reasons above to

[GO BACK](#)
<https://www.prepareforyourcare.org/>

Health care agents:



- Think about this role as an act of love.
- If you accept this role, commit to it.
- Trust yourself to do what is right.
- The person who chose you trusts that you can – and will.

Last night, my kids and I were sitting in the living room and I said to them , 'I never want to live in a vegetative state, dependent on some machine and fluids from a bottle. If that ever happens, just pull the plug.'

They got up, unplugged the computer, and threw out my wine.



Talk to your agent about:

- What experiences or activities are most important for you to live well?
- What helps you when you face serious challenges in your life?



Choose flexibility for your agent

“I trust you to work with my doctors. It’s okay if you have to change my prior decisions if something is better for me at the time.”

or

“It’s okay if you have to change my prior decisions, but there are some decisions that I never want you to change. These decisions are...”

or

“Follow my wishes exactly, no matter what.”

How to Begin - #2

✓ Explore religious, spiritual, cultural or personal beliefs

- What beliefs (if any) do you have that might help you choose the care you want - - or do not want?
- Are there practices that are important to you or give you comfort?
- Do you want to discuss these beliefs or make your concerns clear to others?

How to Begin - #3

✓ Explore your goals for medical care



Exploring goals of treatment

Imagine this scenario:

A sudden event (such as a car accident or serious illness) left you unable to communicate. You are receiving all the medical treatment needed to keep you alive, but the doctors believe there is little chance you will ever recover the ability to know who you are or who you are with.

In your own words, tell me what this situation means.

What would you want?

Assume you would be kept comfortable, no matter what treatments you would want or not want.



Would you want life sustaining treatments to continue or would you want to be allowed to die a natural death?

Can You and Your Loved Ones Answer These Questions?

- On a scale of 1 to 5, where do you fall on this continuum?
 1 ————— 2 ————— 3 ————— 4 ————— 5
Let me die without medical intervention *Don't give up on me no matter what, try any proven and unproven intervention possible*
- If there were a choice, would you prefer to die at home, or in a hospital?
- Could a loved one correctly describe how you'd like to be treated in the case of a terminal illness?
- Is there someone you trust whom you've appointed to advocate on your behalf when the time is near?
- Have you completed any of the following: written a living will, appointed a healthcare power of attorney, or completed an advance directive?

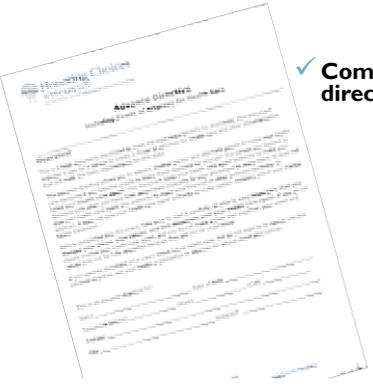
engagewithgrace.org The One Slide Project

Remember

- Be patient.
- Don't steer the conversation, let it happen.
- Don't judge. Living well means different things to different people.
- Every attempt at the conversation is valuable.
- This is the first of many conversations – you don't have to cover everyone or everything right now.
- Nothing is set in stone. You and your loved ones can always change your minds as circumstances shift.



Document the Discussion



✓ Complete an advance directive

What is an Advance Directive?

Advance Directive
A document with two parts

Legal Part
(Power of Attorney for Health Care)
Laws vary from state to state

Values Part
(Patient values and preferences)

Learn more at www.honoringchoiceswi.org. The name "Honoring Choices Wisconsin" is used under license from the Twin Cities Medical Society Foundation.

Honoring Choices WISCONSIN
AN INITIATIVE OF THE WISCONSIN MEDICAL SOCIETY

Then...

- Give copies to your health care agent and health care professionals.
- Talk to the rest of your family and close friends. Tell them who your health care agent is and what your wishes are.
- Keep a copy of your advance directive where it can be easily found.
- Take a copy with you if you go to a hospital or nursing home and ask for it to be put in your medical record.

Review periodically

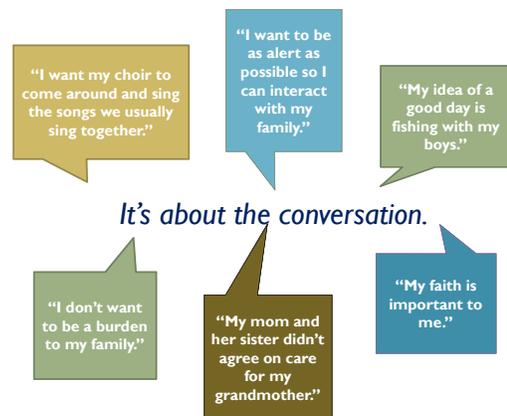


- Advance care planning is a process, not a one-time event.
- Wishes may change as circumstances change.
- Review your wishes every time you have a physical exam.

And...

Whenever any of the “Five D’s” occur:

- *Decade*
- *Death of a loved one*
- *Divorce*
- *Diagnosis*
- *Decline*



It's about the conversation!

Available at www.HonoringChoicesWI.org

- 10-minute version
- 3-minute version
- 3-minute version with Spanish subtitles

“Our ultimate goal, after all, is not a good death but a good life to the very end.”

Atul Gawande, MD

Author, *Being Mortal: Medicine and What Happens in the End*



Questions?

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