

Advance
Care
Planning:
It's About the Conversation



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The name Honoring Choices Wisconsin is used under license from the Twin Cities Medical Society Foundation.

Objectives

- Define advance care planning
- Describe Honoring Choices Wisconsin
- Provide tools for engaging in advance care planning



Advance Care Planning is:

A process of ...

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

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



Advance Care Planning includes:

- Understanding your health care treatment options
- Clarifying your health care goals
- Weighing your options about what kind of care and treatment you would want or not want
- Making decisions about whether you want to appoint a health care agent or complete an advance directive
- Communicating your wishes and any documents with your family, friends and health care provider



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Why is this important?



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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. . . .



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Why is this important?

- The care you receive may not reflect your wishes



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Why is this important?

- The care you receive may not reflect your wishes
- Your health care providers may not know your treatment preferences



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Why is this important?

- The care you receive may not reflect your wishes
- Your health care providers may not know your treatment preferences
- Your family may be left wondering if they are making the right decision



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60% Don't want to burden

56% Have not communicated their wishes

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70% Prefer to die at home

70% die in an institution

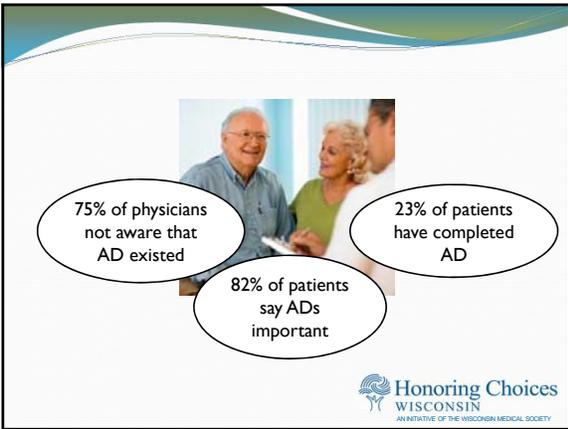
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80% would like doctor to talk about EOL

7% say doctor has talked about EOL

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75% of physicians not aware that AD existed

82% of patients say ADs important

23% of patients have completed AD

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The mission of Honoring Choices Wisconsin is to promote the benefits of and improve processes for advance care planning across the state, in health care settings and in the community.

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- 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 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 specific instructions that reflect 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



First Steps®	Next Steps	Last Steps®
Create an AD that identifies healthcare agent and goals of care for permanent brain injury	Identify goals of care, if illness complications result in "bad outcomes"	Identify goals of care, expressed as medical orders using POLST paradigm
Healthy adults or those who have not planned	Individuals with advanced illness, complications, frequent encounters	Individuals whom it would not be a surprise if they died in the next 12 months

“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, Wenger, Shugartman, 2007)



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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)



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From Documents to Conversations?

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



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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

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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)

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ACP: Helping Achieve the Triple Aim

Retrieved from: www.hl.org/Engage/Initiatives/TripleAim

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Improve Patient Care

- 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



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Improve Population Health

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



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Control Per-Capita 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



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Cost of Care in the Last Two Years of Life

Hospital	Inpatient Days per Descendent Last 2 Years of Life, 2010	Total Medicare Reimbursement of Care/Patient Last 2 Years of Life, 2010
Gundersen Health System	9.7	\$48,771
University of Wisconsin	18.9	\$67,734
Cleveland Clinic	25.5	\$86,279
Mayo Clinic	17.5	\$72,444
UCLA	28.5	\$137,248
New York Univ. Medical Center	32.3	\$131,624
National Average	14.4	\$58,886

Source: Based on 2010 Dartmouth Atlas Study Methodology. The Dartmouth Atlas methodology examines hospital inpatient care for the last two years of a Medicare patient's life.

What does every competent adult need to plan for?



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We can't predict the future



Sudden accident or illness leaving you unable to make your own health care decisions.



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How to Begin

1. Reflect on your values
2. Choose a decision-maker
3. Explore your goals for medical care
4. Complete an advance directive



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How to Begin: #1



Clarify your beliefs

- ✓ Experiences
- ✓ Culture
- ✓ Religion
- ✓ Family Traditions
- ✓ Friendships



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Looking back...

Did anything happen in the past that shaped your feelings about medical treatment?

- What was positive about that experience?
- What do you wish would have been done differently?
- What did you learn from that experience?



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Here and now . . .

- Do you have significant health problems now?
- What kinds of things bring you such joy that, if a health problem prevented you from doing them, life would have little meaning?



If ill . . .



- Do you understand your illness and the complications that may occur?
- What fears or worries do you have about your illness or medical care?



How to Begin - #2

✓ Choose a decision-maker (health care agent)



Ask someone who...



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Ask someone who:

- Can be trusted
- Is willing to accept this responsibility
- Is willing to follow your wishes, even if he or she does not agree with them
- Can manage conflict and make decisions in sometimes difficult situations



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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



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PREPARE

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

- 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

<https://www.prepareforyourcare.org/>

GO BACK

To health care agents:

- Think about being prepared for 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.

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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:

- Your understanding of your current health or illness
- Your fears or worries for the future
- Your goals and priorities
- What outcomes are unacceptable to you and what you are and are not willing to sacrifice
- What a good day would look like

Being Mortal, Atul Gawande, MD



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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."



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How to Begin - #3

✓ **Explore your goals for medical care**



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How to Begin - #3

✓ Explore your goals for medical care



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How to Begin - #3

✓ Explore your goals for medical care



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THE GO WISH GAME

LOAD PREVIOUSLY SAVED GAME

HOME | MY WISH SPACE | PURCHASE | FAQS | RESOURCES | SUPPORT | ABOUT US | STORES

Welcome to Go Wish!

Go Wish gives you an easy, even entertaining way to talk about what is most important to you. The cards help you find words to talk about what is important if you were to be living a life that may be shortened by serious illness. Playing the game with your relatives or best friends can help you learn how you can best comfort your loved ones when they need you most. Read more...

GO WISH QUOTES...

When is the best time to plant a tree? 20 years ago.

When is the next best time? Today!

Try It FREE! Buy It!

Play the Online Version for FREE!

Click on this link to play the online interactive version of the game.

LEARN HOW People Use Go Wish

STORIES OF PEOPLE WHO HAVE USED GO WISH

ADULT WITH ELDER PARENTS COUPLE IN TRANSITION
NEW PARENTS HEALTH CARE PROFESSIONAL & CLIENT
PERSON WITH UPCOMING MEDICAL PROCEDURE

MORE

Remember

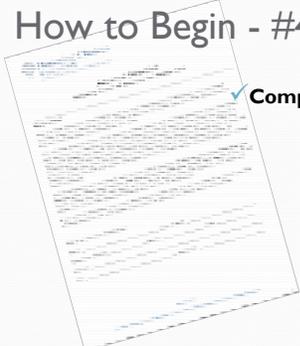
- Be patient.
- Don't steer the conversation, let it happen.
- Don't judge. A "good" death means different things to different people.
- Every attempt at the conversation is valuable.
- This is the first of many conversations – you don't have to cover everyone or everything right now.
- Nothing is set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

The Conversation Project (2013)



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How to Begin - #4



✓ Complete an advance directive



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What is an Advance Directive?

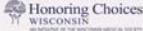


Advance Directive
A document with two parts

Legal Part
Power of Attorney for Health Care
Learn why from slide 49 slide

Values Part
Patient wishes and preferences

Learn more at www.honoringchoices.org
The Right Honoring Choices document is available
through the Right Honoring Choices document.
Sponsored by the Right Honoring Choices Foundation.



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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.



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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.



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And...

Whenever any of the "Five D's" occur:

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



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"I want my choir to come around and sing the songs we usually sing together."

"I want to be as alert as possible so I can interact with my family."

"My idea of a good day is fishing with my boys."

It's about the conversation.

"I don't want to be a burden to my family."

"My mom and her sister didn't agree on care for my grandmother."

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It's about the conversation!

Available at www.HonoringChoicesWI.org

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

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Questions?

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