Mom, I Think We Should Talk:
Preparing for the Final Transition

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Planning for end of life care is not about how a person wants to die, but rather how they want ***to live*** until the final transition.

Caveat Emptor
(Let the buyer beware.)

- ~~Doctor, nurse or attorney~~
  - Social Worker
- ~~Work in hospital, hospice or nursing home~~
  - Consumer health information

✓ Consumer advocate

✓ Family caregiver

✓ Involved

✓ More than moderately opinionated

What do Americans Want?

- To die at home
- Our pain and symptoms controlled
- Our wishes known and honored
- Treated as a whole person
- To know that our loved ones will be cared for

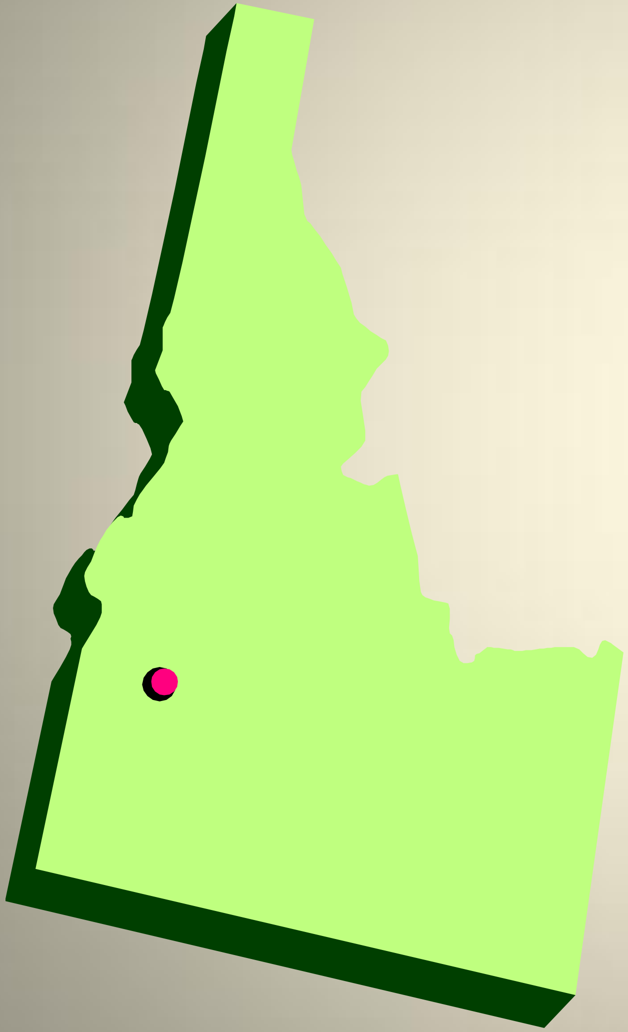
Tyler B, Perry M, Lofton T, and Millard F. *The Quest to Die with Dignity: An Analysis of Americans' Values, Opinions, and Attitudes Concerning End-of-Life-Care*, RWJF, 1997


© Corbis

“Modern medicine is good at staving off death with aggressive interventions—and bad at knowing when to focus, instead, on improving the days that terminal patients have left.”

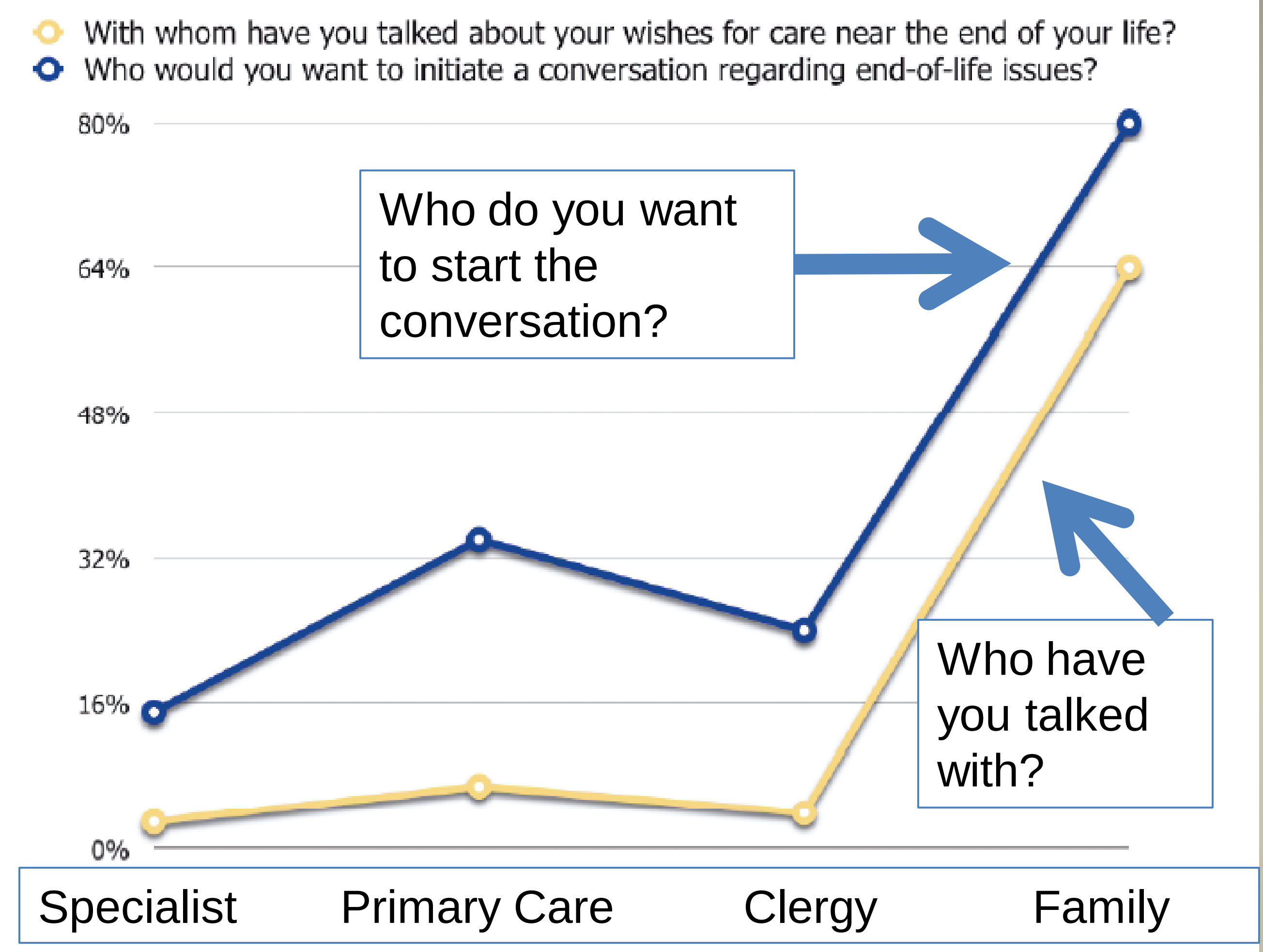
From the article “Letting Go” by Atul Gawande, MD
The New Yorker, August 2, 2010

Idaho: Ready but Reluctant



"People in Idaho are comfortable talking about death and are familiar with advance healthcare planning, but often have not had key end-of-life conversations and many have not taken action to express their wishes."

From Simpson-Whitaker, C, Totten, AM, Moffat-Miller, C. *"Idaho Statewide End-of-Life Survey Report, 2006"*. A Better Way Coalition & The Center for the Study of Aging, BSU.



Who do you want to start the conversation?

Who have you talked with?

Specialist Primary Care Clergy Family


BOISE STATE Center for the Study of Aging

A Better Way Coalition
LIFE ON OUR OWN TERMS

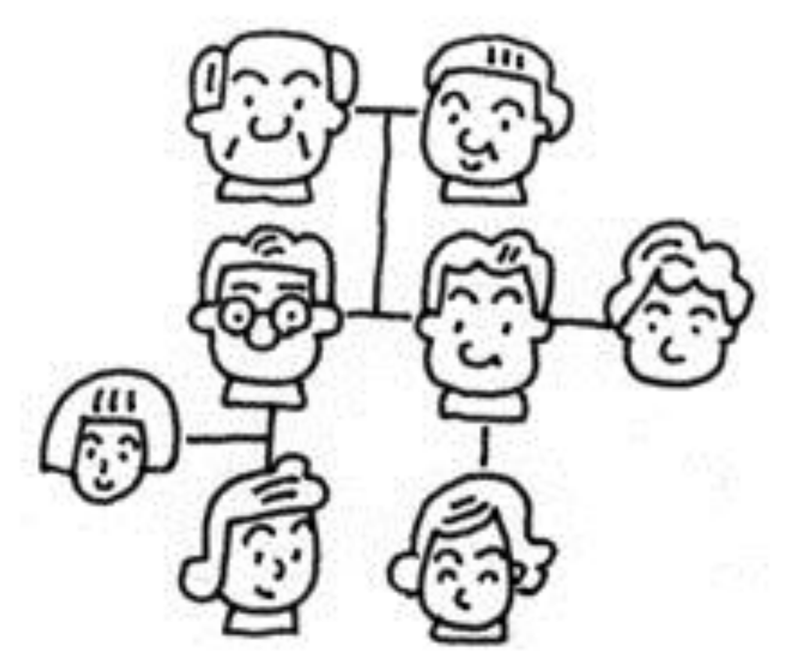
IDAHO END-OF-LIFE SURVEY

Fall 2006

Communicating Wishes

Page 1

Every person. Every family.



- Define & Decide
- Delegate & Discuss
- Document

Define:
Understand what the words mean.

Decide:
What are your preferences for care? What is important to you?

How the Pros Talk:

- Coma
- Persistent Vegetative State
- CPR
- DNR
- Living Will
- Advance Directive
- Palliative Care
- Hospice Care
- POLST/POST/MOST/MOLST

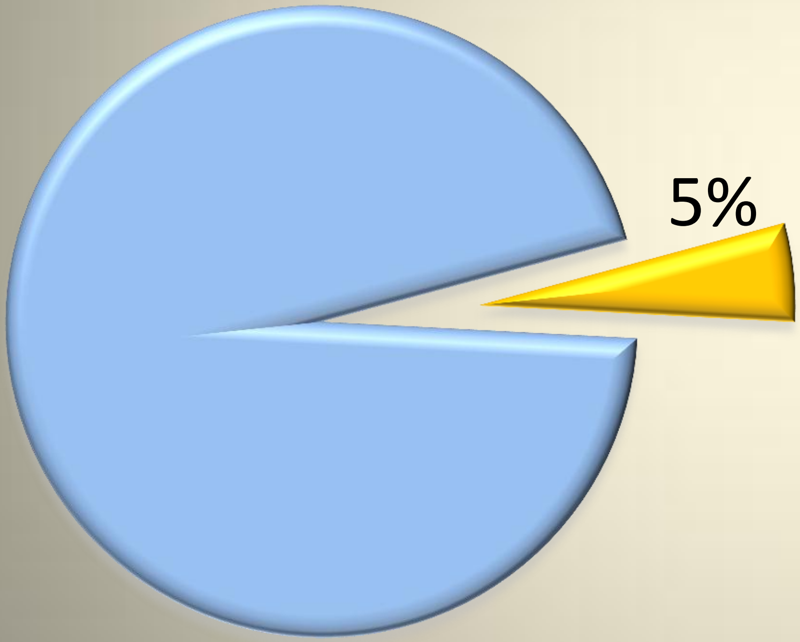
- Artificial nutrition
- Artificial hydration
- Antibiotics
- Blood products
- Ventilation
- Aggressive interventions
- Limited additional interventions
- Comfort measures

How the People Talk

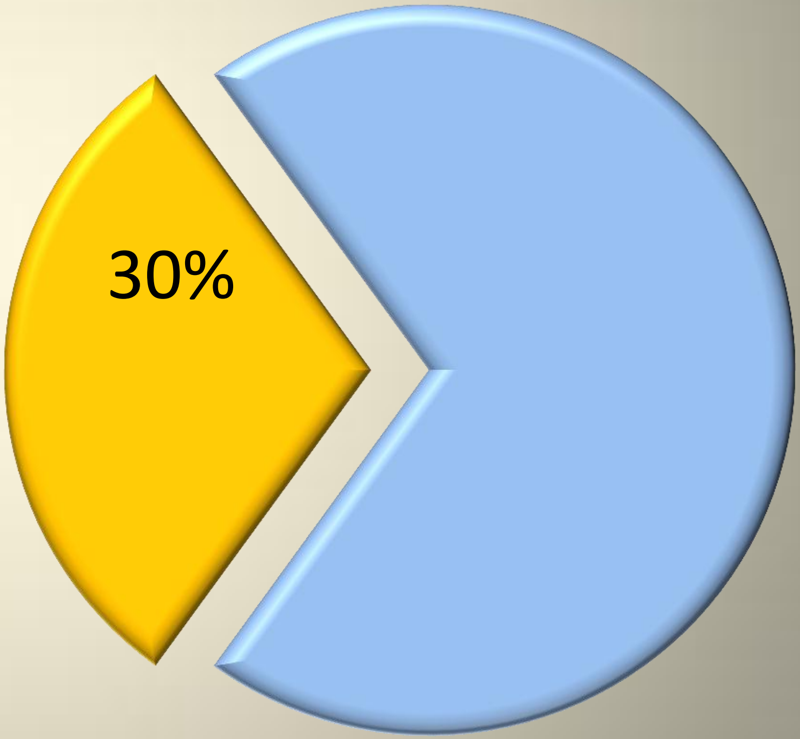
- “I don’t want to be hooked up to a lot of tubes.”
- “I don’t want to have to depend on other people to take care of me.”
- “When it’s time, it’s time.”
- “Give Mom everything you’ve got.”
- “I want to die at home.”
- “I’m afraid of pain.”
- “Hospice? Are you giving up on Dad?”

I’m about to editorialize.

We Need to Do Better for Everyone



Medicare Enrollees



Medicare Expenses

“Health care costs in the last week of life, Arch Intern Med.2009; 169 (5): 480-488

Increase in elderly poverty

“Out-of-pocket health care expenditures incurred prior to the death of a spouse are partially responsible for impoverishment of the surviving spouse.”

Chao, L, Pagan, J, et al, End-of-Life Medical Treatment Choices
Med Decis Making. 2008; 28(4): 511–523.

Define:
Understand what the words mean.

Decide:
What are your preferences for care?
What is important to you?

Balancing What’s Important

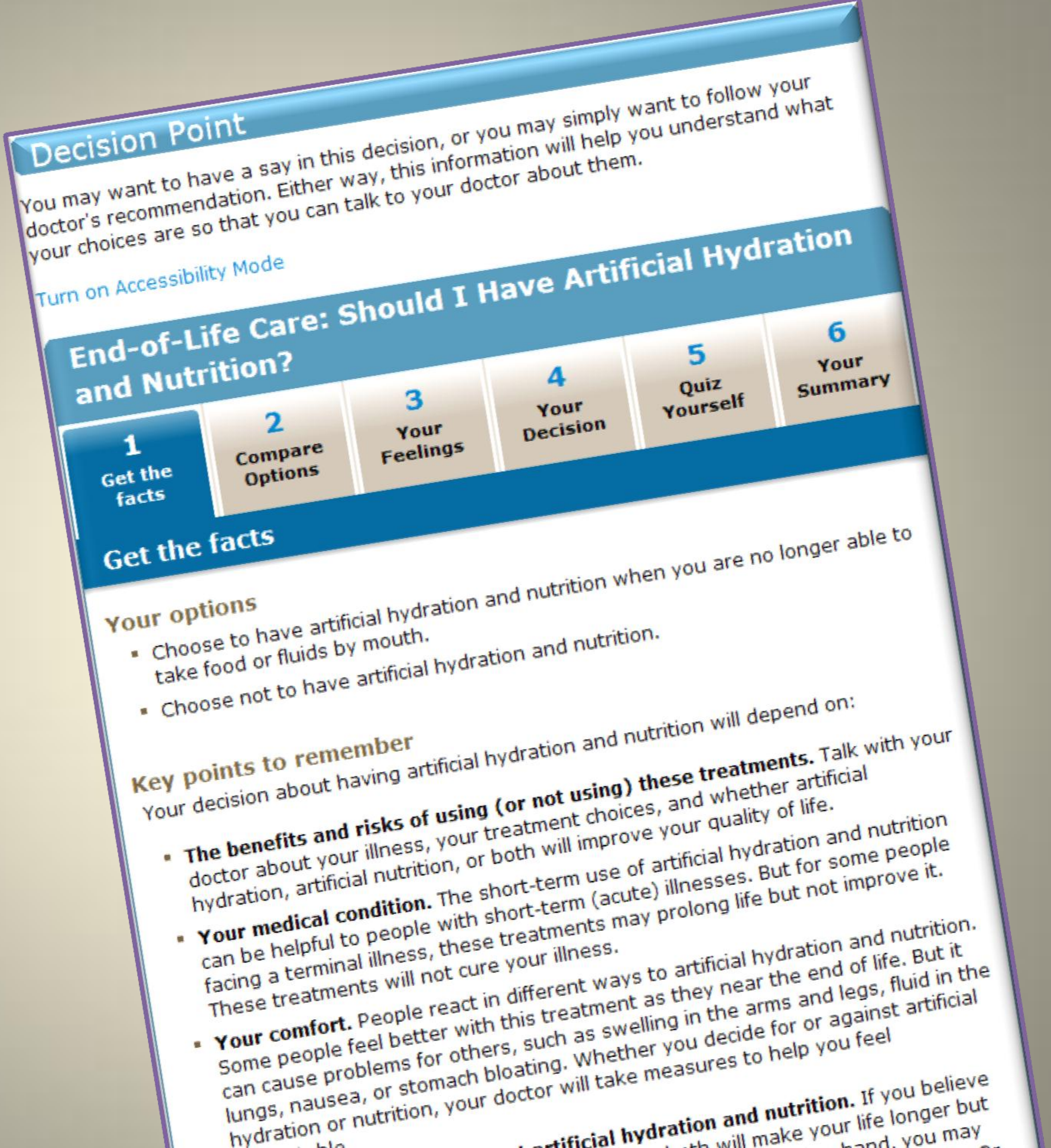
Medicine

Personal values

The medical facts

+

Personal values and preferences



Decision Point

You may want to have a say in this decision, or you may simply want to follow your doctor's recommendation. Either way, this information will help you understand what your choices are so that you can talk to your doctor about them.

Turn on Accessibility Mode

End-of-Life Care: Should I Have Artificial Hydration and Nutrition?

Get the facts

Your options

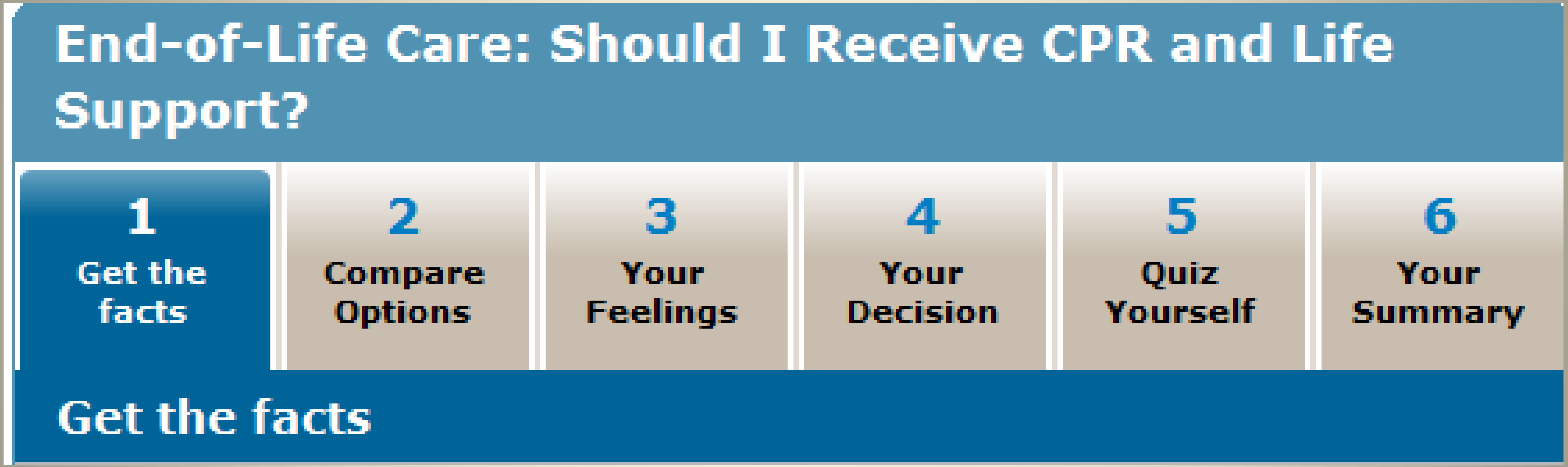
- Choose to have artificial hydration and nutrition when you are no longer able to take food or fluids by mouth.
- Choose not to have artificial hydration and nutrition.

Key points to remember

Your decision about having artificial hydration and nutrition will depend on:

- **The benefits and risks of using (or not using) these treatments.** Talk with your doctor about your illness, your treatment choices, and whether artificial hydration, artificial nutrition, or both will improve your quality of life.
- **Your medical condition.** The short-term use of artificial hydration and nutrition can be helpful to people with short-term (acute) illnesses. But for some people facing a terminal illness, these treatments may prolong life but not improve it. These treatments will not cure your illness.
- **Your comfort.** People react in different ways to artificial hydration and nutrition. Some people feel better with this treatment as they near the end of life. But it can cause problems for others, such as swelling in the arms and legs, fluid in the lungs, nausea, or stomach bloating. Whether you decide for or against artificial hydration or nutrition, your doctor will take measures to help you feel

artificial hydration and nutrition. If you believe
will make your life longer but
hand, you may



End-of-Life Care: Should I Receive CPR and Life Support?

Get the facts

Resources for Define & Decide

For Individuals and Families:

www.webmd.com

Search | Care at the End of Life – Important Decisions

For Professionals

- www.acpdecisions.org

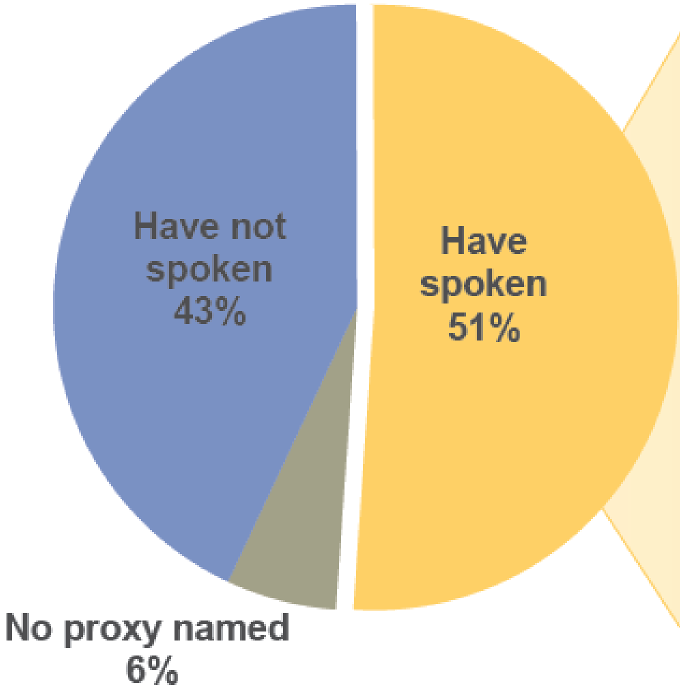
Delegate & Discuss

Communicate your Choices

- Who will speak for you if you cannot?
- In MI: ***Patient Advocate***
- Inform family <u>and</u> doctors

Conversations About End-of-Life Wishes

Which of the following best describes the conversations you've had with your proxy*?



Passing remarks 6% (3% of total)

Casual, without too much detail 37% (19% of total)

Serious, in-depth conversations 56% (29% of total)

*Proxy: Not used in the legal sense, it includes any relatives or friends named by respondents who would make medical decisions for them.
Source: End-of-Life Issues and Care in California, statewide survey of 1,778 adults, conducted by Lake Research Partners for the California HealthCare Foundation, March to April 2006.

Talk is Good

- Less fear and anxiety
- More empowered
- Better understanding with doctors (1)

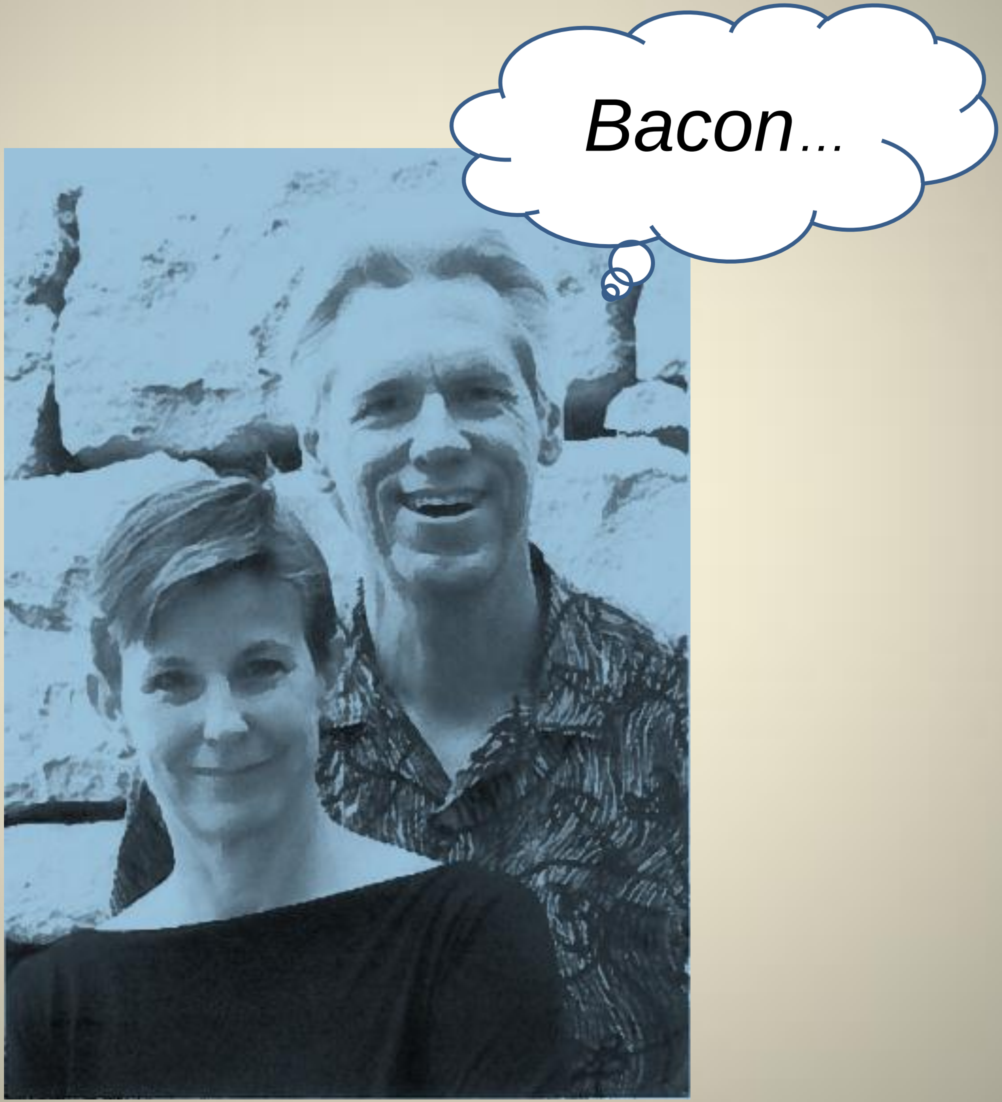
____

- Fewer life-prolonging procedures
- Lower ICU admissions (2)

(1) AHRQ, Advance Care Planning, Research in Action, Issue 12

(2) Zhang B, Wright AA, Huskamp HA, Nilsson ME, Laciejewski ML, et al. Health care costs in the last week of life. *Arch Intern Med* 2009;169(5):480—489. http://www.ncbi.nlm.nih.gov/pubmed/19273778

Delegate & Discuss



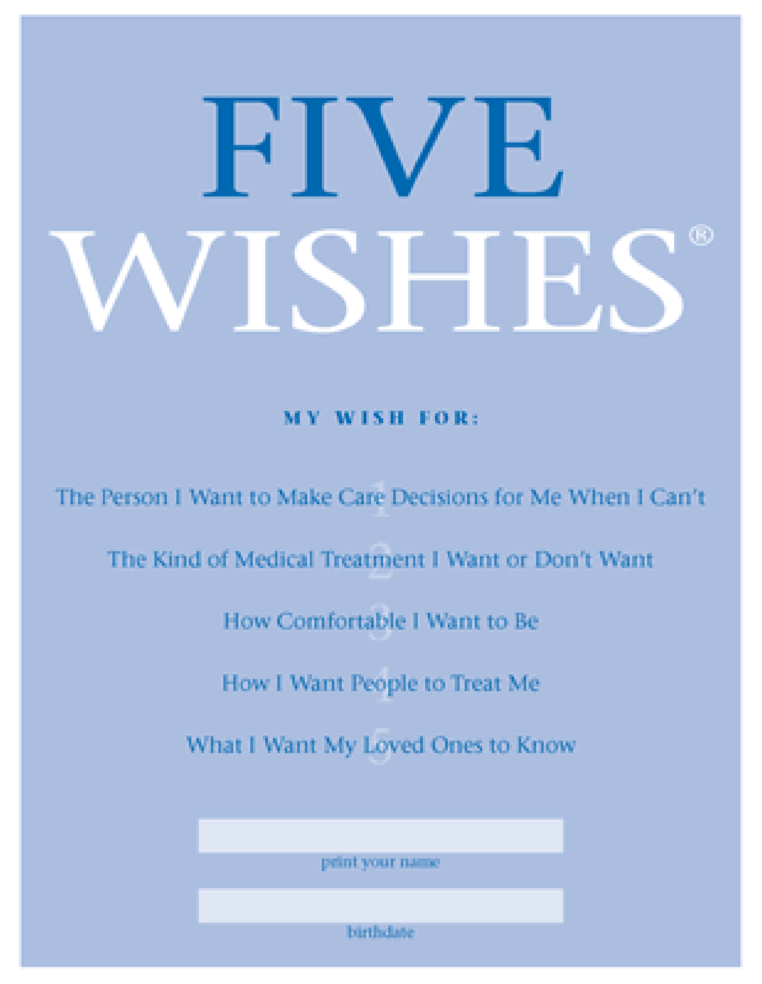
Sometimes….
People aren’t ready to talk.

Consumer's Toolkit for Health Care Advance Planning: 10 Tools

- How to select your proxy
- Personal priorities & spiritual values
- How to have "The Conversation"
- What to do after signing your Advance Directive
- Guide for proxies

www.americanbar.org

Family Resources



FIVE
WISHES®

MY WISH FOR:

1 The Person I Want to Make Care Decisions for Me When I Can't

2 The Kind of Medical Treatment I Want or Don't Want

3 How Comfortable I Want to Be

4 How I Want People to Treat Me

5 What I Want My Loved Ones to Know

print your name

birthdate

- **Aging with Dignity**

www.agingwithdignity.org/five-wishes

Document. Document. Document.

- < 50% of seriously ill patients had an AD in their medical record
- Only 12% of patients with an AD had gotten input from their doctors
- Between 65-76% of doctors whose patients had ADs were not aware it existed.

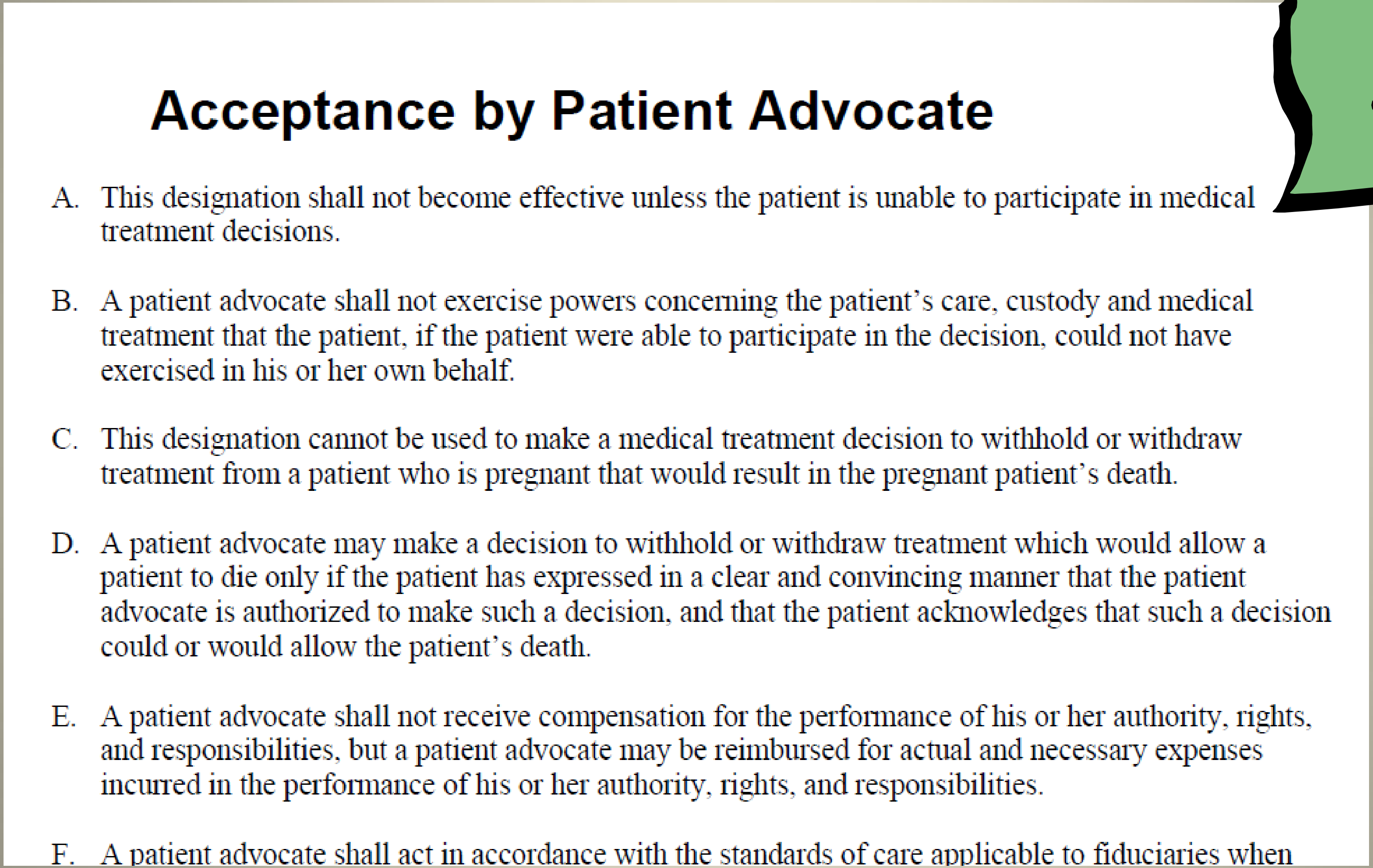
The U.S. Agency for Healthcare Research and Quality, in a 2003 article (10),
“Advance Care Planning: Preferences for Care at the End of Life,”

Resources for Documenting

For Michiganders…Michiganites….Michiganians

- Caring Connections (NHPCO)
  - www.caringconnections.org
- Blue Cross/Blue Shield of Michigan
  - www.bcbsm.com

In Michigan



Acceptance by Patient Advocate

A. This designation shall not become effective unless the patient is unable to participate in medical treatment decisions.

B. A patient advocate shall not exercise powers concerning the patient's care, custody and medical treatment that the patient, if the patient were able to participate in the decision, could not have exercised in his or her own behalf.

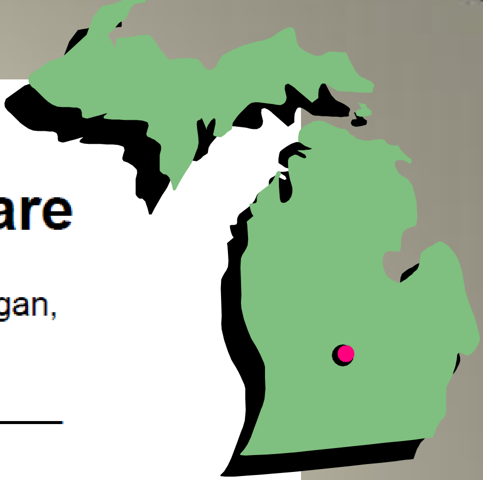
C. This designation cannot be used to make a medical treatment decision to withhold or withdraw treatment from a patient who is pregnant that would result in the pregnant patient's death.

D. A patient advocate may make a decision to withhold or withdraw treatment which would allow a patient to die only if the patient has expressed in a clear and convincing manner that the patient advocate is authorized to make such a decision, and that the patient acknowledges that such a decision could or would allow the patient's death.

E. A patient advocate shall not receive compensation for the performance of his or her authority, rights, and responsibilities, but a patient advocate may be reimbursed for actual and necessary expenses incurred in the performance of his or her authority, rights, and responsibilities.

F. A patient advocate shall act in accordance with the standards of care applicable to fiduciaries when

Courtesy of www.bcbsm.com



Durable Power of Attorney for Health Care

I, ______________________________ of ______________________ Michigan,
(Name) (City)

hereby appoint ____
(Patient Advocate)

residing at
____,
(Patient Advocate Address)

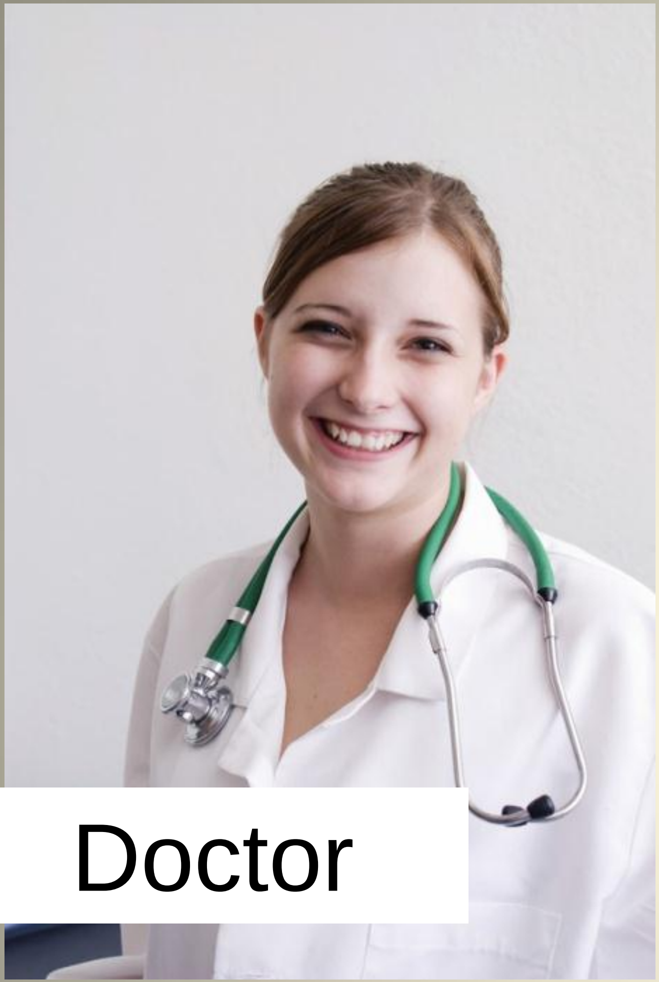
as my attorney in fact (herein called patient advocate) with the following power to be exercised in my name and for my benefit, including, but not limited to, making decisions regarding my care, custody or medical treatment. This power of attorney has effect only if I become unable to participate in treatment decisions.

If the first individual is unable, unwilling or unavailable to serve as my patient advocate, then I designate
____, residing at
(Successor Patient Advocate)

____, to serve as my patient advocate.
(Successor Patient Address)

With respect to my personal care, my advocate shall have the power to make each and every judgment necessary for the proper and adequate care and custody of my person, including, but not limited to:

Courtesy of www.bcbsm.com



Doctor

Advocate

Family

Every person. Every family.

- Define & Decide
- Delegate & Delegate
- Document

Thank you.

A National Groundswell

- April 16: National Healthcare Decisions Day
- Engage with Grace
- Coalition to Transform Advanced Care
- American Academy of Nurses

RAISE THE VOICE
CRITICAL CONVERSATION
BEST PRACTICES IN ADVANCED CARE PLANNING AND DECISION MAKING: MODELS THAT WORK

CONVERSATION VIDEO
click here to view