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

“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
“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.”

Who do you want to start the conversation?

Who have you talked with?

- Specialist
- Primary Care
- Clergy
- Family
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

5%

30%

“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.”

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

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

- 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 more comfortable.

- Artificial hydration and nutrition. If you believe artificial hydration and nutrition will make your life longer but not improve your comfort, you may find it difficult to continue.
Resources for Define & Decide

For Individuals and Families:

www.webmd.com

For Professionals

- www.acpdecisions.org
Delegate & Discuss
Communicate your Choices

- Who will speak for you if you cannot?
- In MI: *Patient Advocate*
- Inform family and doctors
Conversations About End-of-Life Wishes

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

- Have spoken 51%
- Have not spoken 43%
- No proxy named 6%
- 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.
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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

Delegate & Discuss

Bacon...
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

- Aging with Dignity

www.agingwithdignity.org
/five-wishes
• < 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
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
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
______________________________
(Successor Patient Advocate)

______________________________, residing at
(Successor Patient Advocate Address)

______________________________, 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:
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