

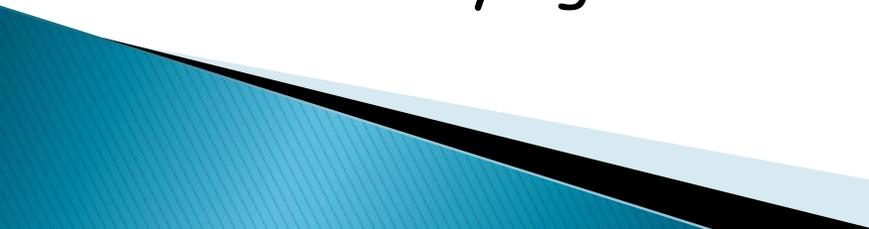
Thinking & Acting Before Dying

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End of Life Choices are Difficult

- ▶ Many families struggle with both discussions and decisions about medical care choices at the end of life.
- ▶ In the worst cases the discussions become arguments that result in hurt feelings and strained relationships.
- ▶ Discussing specific types of medical choices before you must to make them helps families work through their feelings. This helps prepare them for when they must decide and act.

End of Life Choices are Difficult

- ▶ When we think about such difficult choices carefully, we become less afraid of them and more empowered to make them well.
 - ▶ When we do not think, discuss and act upon these choices ahead of time, we set our families up for confusion & uncertainty.
 - ▶ That often leads to **conflict** within the family or with the medical care team.
 - ▶ Much **conflict can be avoided** by thinking and acting before dying.
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Multi-Stage Process

- ▶ These are BIG decisions; The FLIP process will help you get clear on the important parts of it.
- 1. Start by writing your personal thoughts in an *easy, narrative story* form.
Be an author, not a lawyer.
- 2. Condense the key points into an instruction plan.
- 3. Share the plan with trusted other people.
- 4. Revise the plan until you are satisfied with it.

Stage 1

- ▶ Write out, then discuss your 1st draft of instructions with trusted others and ask them 2 questions:
 1. Is my *plan clear*? Does it *make sense*?

“No Heroic Treatments”



What does that mean?



Can I still wear my cape?

Stage 1

2. Does it sound like it **came from me?**

Listen to their feedback!

Revise your plan --

only in response to the feedback
that resonates with you.

Explain why you are not accepting all
the feedback offered; it's your life!

Stage 2

- ▶ Repeat this process with your **most trusted key people**: those who will be at your bedside 24 to 48 hrs. after learning of your illness.
- ▶ When you have a final version, date and sign it.
- ▶ Revisit the instruction plan every year on your **birthday**. Consider it your birthday gift to your loved ones.

Key Points

- ▶ These are **instructions**, not wishes; they have the power of legal enforcement even over the objections of others.
- ▶ **Expect to revise** the instructions as your medical conditions and personal relationships change over time.
- ▶ *Pick your proxy carefully*; he or she must agree with the content, purpose, spirit & goals of your directives. *Get their agreement in writing!*

Stage 3

- ▶ Share the instruction plan with your **physician & attorney**.
- ▶ Ask them if they have questions, or suggestions to make it clearer.
- ▶ Ask if they would have any difficulty agreeing to abide by (physician) and support (attorney) your instructions.
- ▶ Give them signed and dated copies of the instruction plan and tell them who else has copies.

If Only We Could See What is Ahead



Confounders

- ▶ A decision about “best” medical care is a best guess; all treatments have some *uncertainty* about the outcome, and many have *unanticipated problems*.
- ▶ Uncertainty and problems do *not* indicate poor care - both are fairly common, especially at the end of life.
- ▶ In addition to *treatment* options, there may be potentially beneficial *research* options to consider. You *must ask* your physician about exploring these.
- ▶ Stopping certain procedures is *not stopping treatment or stopping care*. It is *changing strategy*.

Confounders



Confounders



Confounders

- ▶ Sometimes families create their own confounders to the treatment decision process.
 1. Family members who try to “parachute” in to the hospital to “rescue” you, especially if they have not been in touch for along time. This usually is intended more to *help them feel better* than to provide *you* with real help.
 2. Family members’ decisions can freeze up due to fear of being blamed for a bad outcome; esp. if deciding to stop or forego treatment.

Advance Directives

- ▶ An Advance Directive is a written document about what medical care you want in the event you can no longer make decisions or communicate them.
- ▶ There are two main types of ADs.
 1. Living Will
 2. Proxy Assignment

Advance Directives

- ▶ *Living Will* - a list of treatments you **permit** & a list of treatments you **refuse**, and the *reasons why* for each one.
- ▶ *Proxy (surrogate) Assignment* - naming another person to act on your behalf with full authority to consent or refuse treatment.

Should include contact information 24/7, and also name a back-up proxy.

Special Instructions – Not ADs

- ▶ **POLST** – Physician Orders for Life Sustaining Treatment.
- ▶ *These are **medical orders** written by your physician that direct other physicians to provide specific medical treatments for you.*
- ▶ Started in Oregon in early 1990s, now in 12 states *but **not (yet) in Michigan.***

Functional Loss Instruction Plan

- ▶ Imagine that you have lost some or all of your ability to reason and/or communicate.
- ▶ You are judged by your physician to be incompetent.
- ▶ Think about what that means until you get used to the idea that *it really has happened to you.*
- ▶ Consider how your incompetence may vary in 3 ways:
 1. It is *temporary* and you will fully recover.
 2. It is *transient* and you will recover, but maybe relapse.
 3. It is *permanent*.

Functional Loss Instruction Plan

- ▶ Your incompetency may include one or more of the following features (cognitive impairments):
 1. Confusion, diminished ability to mentally focus
 2. Short term memory loss
 3. Anxiety, insomnia, fatigue
 4. Diminished *awareness* of surroundings
 5. Diminished *orientation* to self, place, time
 6. Diminished *consciousness*
 1. Chronic sleepiness
 2. Unconsciousness

Functional Loss Instruction Plan

- ▶ Your cognitive impairments:
 1. May range from minimal to severe
 2. May occur suddenly or gradually
 3. May be side effects of medications
 4. May be temporary, recurring or permanent

Your written instructions should reflect how the different manifestations of your incompetence should affect which treatments your proxy permits and which he or she refuses on your behalf.

Functional Loss Instruction Plan

- ▶ In addition to cognitive impairments you also may experience one or more of the following:
 1. Reduced or lost independent mobility
 2. Reduced or lost bladder/bowel control
 3. Reduced or lost vision clarity (e.g., no TV, reading)
 4. Reduced or lost hearing (e.g. no TV or reading)
 5. Reduced or lost appetite, frequent nausea
 6. Reduced or lost ability to self-feed
 7. Insomnia, irritability and/or constant fatigue
 8. Increased sensitivity to pain or discomfort

Functional Loss Instruction Plan

- ▶ Consider each scenario and their different combinations.
- ▶ Your reaction to them will help clarify which functions are most valuable to you - what makes life worth living to you.
- ▶ When you describe which abilities make life worth living to you and why, your proxy can better evaluate choices about treatments to permit and to refuse. This is important because the treatment may be expected to do 3 things:
 1. *improve or correct* the disability
 2. *prevent disability from worsening*
 3. have an *unknown effect* on the disability

Functional Loss Instruction Plan

- ▶ No one can imagine all the possible scenarios that arise in life, illness, accidents, and how individuals respond to medical care.
 - ▶ No advance directive can ever be comprehensive; each one will be inadequate in one way or another.
 - ▶ Therefore, your proxy should have discretionary authority to respond to unanticipated developments and problems.
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The Most Difficult/Feared Case

- ▶ Cognitive impairment → incompetency
- ▶ + combined with serious functional losses
- ▶ that reduce one's quality of life to below a personally acceptable threshold
- ▶ with no reasonable prospect of improvement.

- ▶ But the underlying medical condition is neither fatal, nor terminal, e.g., advanced dementia + immobile.
- ▶ And your care needs are minimal; food & water & personal hygiene.

- ▶ The best AD narratives will guide the proxy's decisions on what to permit and what to refuse.

New Standards Emerging

- ▶ Commission on Assisted Dying (UK) has recommended the government end criminalization of assisted suicide in specific cases.
 1. If an individual is 18+ years
 2. terminal illness
 3. mental capacity to make an informed choice
 4. unimpaired by depression
 5. free of influence of others
 6. they should have the right to request an assisted death.

New Standards Emerging

- ▶ Safeguards: skilled professionals who can
 1. confirm their diagnosis and
 2. explore their reaction to and understanding of their:
 1. health condition,
 2. motivation for their request,
 3. voluntariness of their choice
 4. decision-making capacity

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▶ Questions or comments?

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