Your Life Your Choices: Straight Talk About Tough Issues

Paige Hector, LMSW
Clinical Educator & Consultant
(520) 955-3387
paigehector@gmail.com
www.paigeahead.com

Making and communication health care decisions

Discuss how beliefs and values impact decisions

Explain common medical situations and treatment decisions

What Happens When Family Members Disagree?

HURT FEELINGS

CONFUSION

CONFLICT

STRESS

YOU MAY NOT RECEIVE THE CARE YOU WOULD HAVE WANTED

How Can You Prevent or Minimize Disagreement?

1. The Basics
2. Thought-provoking exercises
3. Health conditions and treatments
4. Your health care preferences
5. How to talk about your wishes

http://www.elderguru.com/download-life-your-life-your
choices-planning-for-future-medical-decisions-workbook/
Limitations of Traditional Advance Directives

May not be available when needed
Not transferred with patient
Not specific enough
May be over-ridden by treating physician
Do not immediately translate into a physician order


Choosing the Right Person

Who do you want to be your “voice” in the event you cannot communicate your wishes?

A spouse, partner or child may **not** be the best choice

Just Ask...

“Would you be willing to represent my views about medical decisions if I can’t speak for myself?”

“Can you make decisions for me that are based on my values, preferences, and wishes – even if they’re not like yours?”

Surrogate Decision Makers

**Arizona Revised Statutes (ARS) § 36-3231**

Statutory regulation outlining Surrogate Decision Makers, (“Chain of Command”)

- Spouse, unless legally separated
- Adult Child or consent of majority of those reasonably available
- Parent of the Patient
- If unmarried, a domestic partner if no other person has assumed any financial responsibility for the patient
- Brother or Sister of Patient
- Close friend who is willing to become involved
- If none of the above, the Physician shall make decisions with guidance of an ethics committee or at least another physician

What are....

values

Beliefs
Values & Beliefs

Values are things (concepts) that are important to us
- Fairness, friendship, financial security, honesty
- We make decisions based on our values

Beliefs are assumptions about the world
- Based on our experiences
- How we see ourselves and other people

Your Beliefs and Values

Use wheelchair to get around
Can’t contribute to family’s well being
Severe pain most of the time
Can’t control my bladder
Can’t recognize family
Severe financial burden on my family
Rely on feeding tube to live*

Life Like This Would Be...

Difficult, but acceptable
Worth living, but just barely
Not worth living
Can’t answer now

What does this mean to you? Would you rather die than be kept alive?

What else do you need to know?

What About….?

If you checked more than one category as “Worth living, but just barely”?

Is there a combination of factors that would make your life “not worth living”?

Pros and Cons of Treatment

Consider...
You are seriously ill...

The doctors are recommending treatment for your illness, but the treatments have very severe side effects (pain, nausea, vomiting, weakness) that could last for 2-3 months.

I would be willing to endure severe side effects if the chance that I would regain my current health was:
- **High** (over 80%)
- **Moderate** (50%)
- **Low** (20%)
- **Very low** (<2%)

And Yet More Choices...

Your Last Days

Avoiding pain and suffering
Being alert even if more painful
Feel someone touching me
Tell my life story and leave good memories
Being at home or in the hospital
Being alive long enough for family to get to my bedside to see me*

What are your biggest hopes about the end of your life?

What are your biggest fears about the end of your life?

Refreshing Concepts

**NATO – Not Attached to the Outcome**
Focus instead on being present in the moment and that in itself is ENOUGH!

**Meaningful Death**
Stop using “Good Death” and “Bad Death” terminology

Greg Yoder, Chaplain
The essence is presence.

Curing and Healing

Curing
Making the problem go away

Healing
Giving someone the resources to deal with problems that will not go away

Rabbi Harold Kushner

Dementia

Loss of memory and other mental functions

Types: Alzheimer’s, AIDS, vascular, result of head injury, alcohol or drug use

Symptoms: inability to concentrate, problem solve, manage personal care, agitation, sexual inhibition, lose sense of day and night, wander, incontinence, loss of interest in eating

Progression is irreversible and worsens over time

Coma

State of unconsciousness

Little to no movement or response to stimulation

Causes: Injury, illness, drug overdose, bleeding in head

After 3-4 weeks considered a persistent vegetative state (PVS)

Total care, including feeding tube

If person comes out of coma, could be permanent brain damage and other limitations

Stroke

Cerebrovascular Accident (CVA)

Blockage in the blood vessel or a burst vessel

#1 cause of disability, 3rd cause of death

Symptoms: weakness or loss of movement, loss of sight, trouble swallowing, aphasia, changes in mood, depression

Chance of having another stroke is high
Terminal Illness

Illness cannot be cured

Prognosis may vary but usually accepted that the person may die within 6 months

Shift to comfort care and palliative medicine

Treatments

Antibiotics

Strong medicines used to treat infections, including life-threatening contagious diseases

Can cause more harm than good when used indiscriminately.

www.familydoctor.org
American Academy of Family Physicians

Antibiotic Resistance

Antibiotics kill bacteria (or stop them from growing)

Some bacteria have become resistant to some types of antibiotics

– Methicillin-resistant Staphylococcus aureus (MRSA)
– Vancomycin-resistant enterococci (VRE)

A few kinds of bacteria are resistant to all antibiotics and are now untreatable

Kidney Dialysis

Process to circulate blood outside the body to remove waste products when the kidneys have failed.

Kidney Dialysis

Pros

• Relieve or lessen some symptoms such as:
  – Feeling sick to stomach
  – Poor appetite
  – Confusion
  – Difficulty breathing
  – Lethargy
• Buy time if waiting for a kidney transplant

Cons

• Time commitment
  – At least 12 hours on the machine plus drive time to center
• Cannot alleviate all symptoms and may still feel poorly
• More prone to infections, bleeding from stomach or bowel, swelling and bloating and more easily fatigued
• Treatment may be difficult to endure, especially if other conditions are present (liver, lungs, heart, musculoskeletal)
**Cardiopulmonary Resuscitation (CPR)**

Chest compressions to stimulate the heart to beat

**CPR**

- Cardiac compression
- Endotracheal intubation
- Artificial ventilation
- Defibrillation
- Advanced cardiac life support drugs

**ORIGINAL Intention for CPR**

To treat sudden, reversible cardiac arrest due to electrocution, drowning or surgical anesthesia problem

...in otherwise healthy persons

**CPR = ICU**

**Words Matter!**

Use “intensive comfort treatment” rather than “comfort measures only”

Use “Allow Natural Death” instead of “Do Not Resuscitate”

Focus on what can be anticipated and what can be done rather than what is not going to be done

David Giansiracusa, MD
Memorial Sloan-Kettering Cancer Center
Mechanical Ventilator (Breathing Machine, Respirator)

Tube (diameter of a dime) placed in the windpipe (through the nose or base of the neck) that allows the machine to breathe for the person.

Mechanical Ventilation

**PROS**
- Painless but uncomfortable
- Can allow the body to recover from an injury or short term illness

**CONS**
- Cannot talk
- Cannot eat
- Totally dependent on others for all personal care
- Usually restricted to bed
- Suctioning of lungs to clear mucus
- May prolong dying

Feeding Tubes

A tube used to carry liquid nutrition and fluids into your body.

- **Nasogastric tube** in the nose (1-4 weeks)
- **PEG tube or G-tube** inserted directly into stomach for long-term supplementation

Original Intention for Artificial Nutrition

Developed for the patient who for a temporary reason cannot eat and drink. Intended for a time-specific duration.

Truth About Artificial Nutrition

- Aspiration is more likely with a feeding tube
- May not achieve weight gain
- May not prolong life or heal pressure ulcers
- May decrease comfort - many times the patient pulls out the tube
- No pleasure of eating
- If confined to bed, getting fluids might make urination difficult to control (risk of skin breakdown)
- If terminal, may postpone death

The Truth About Starvation

Near the end of life, after a few days of not eating or drinking, you no longer experience hunger or thirst.

You are not starving to death.

Forgoing nutrition and hydration near the end of life leads to greater comfort.

The underlying disease process causes death.

Slomka, Jacqueline, PhD, RN. “Withholding nutrition at the end of life: Clinical and ethical issues.” Cleveland Clinic Journal of Medicine, 2003, 70(6), 548-552.
Last Comment on Artificial Nutrition...

Withdrawing support is MUCH MORE DIFFICULT than withholding support.

Of Special Interest in Arizona

According to ARS, Chapter 32 (Living Wills and Health Care Directives), §36-3203, letter E:

“A surrogate who is not the patient’s agent or guardian shall not consent to or approve the permanent withdrawal of the artificial administration of food or fluid.”

Now For The Hard Part

Making Decisions....

Current Health

My life right now is just fine
My life right now is difficult, but acceptable
My life right now is worth living, but just barely
My life right now is not worth living

Preferences for Different Life-Sustaining Treatment

<table>
<thead>
<tr>
<th>Treatment</th>
<th>I would want to receive this treatment</th>
<th>I would rather die naturally and not have this treatment</th>
<th>I don’t know/can’t answer right now</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antibiotics</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CPR</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeding tube: Short time</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dialysis: short time</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dialysis: Rest of my life</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mechanical Ventilator: short time</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mechanical Ventilator: Rest of my life</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comfort Care</td>
<td>✅</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other tx (fill in)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

What is Comfort Care?

Relief from pain and symptoms
Medications to control pain, nausea, fatigue and shortness of breath
Keep your body clean, dry and comfortable
Sometimes includes treatments (antibiotics, chemotherapy, or even surgery)
Severe Dementia

This means you:
- Cannot think or talk clearly, are confused and no longer recognize family members
- Seem uninterested in what's happening around you
- Are not in any pain
- Are able to walk, but get lost without supervision
- Need help with getting dressed, bathing, and bowel and bladder functions

Severe Dementia

Life like this would be difficult, but acceptable
Life like this would be worth living, but just barely
Life like this would not be worth living

55

Severe Dementia

I would want to receive this treatment
I would rather die naturally and not have this treatment
I don't know/can't answer right now

Antibiotics
CPR
Feeding tube: Short time
Rest of my life
Dialysis: short time
Rest of my life
Mechanical Ventilator: short time
Rest of my life
Comfort Care
Other (fill in)

57

Conversation Starters

"[name], I'd like to talk with you about something I discuss with all my patients. It's called advance care planning. In fact, I feel this is such an important topic that I have done this myself with my own physician. Are you familiar with advance care planning?"

"There is no change in your health that we have not already discussed. I am bringing this up now because it is prudent for everyone, no matter their age or state of health, to plan for the future..."

Helping Medical Staff
Start the Conversation

More Conversation Starters...

"We should also consider the situations that your particular illness can cause; that way you can be confident we will do what you want."

"It seems to me that it's really important that you..."

"I'm wondering if you would talk with me about some difficult issues?"

"I would like to make sure I understand what is important to you."

"Some people feel talking about advance directives is frightening. I'm wondering how you feel about it?"

59

Education in Palliative and End of Life Care for Oncology
http://bit.ly/1D4Mv3G

59
The “What If?” Question

“What if things don’t go as we hope they will?”
- Discuss possibilities and consider alternatives
- Discuss what might happen
  • Prevent an issue from becoming a crisis
- Provide a sense of control

Statements to Avoid

“Do you want us to do everything?” or “Would you like us to do everything possible?”
- Elicits a single, reflexive answer, “YES.”
- “Miscommunication occurs because clinicians and families silently complete the phrase very differently.”

Instead say...

“How were you hoping we could help?”
- Examples: “Make my pain better,” “Put that tube in my throat,” “Tell my daughter that I love her,” or “Help me.”

Statements to Avoid

“Stop the machines.”
- Family hears, “You mean you’re just going to stop?”
- Focus is on what will not be done rather than on the care that will be provided
- Suggests an aftermath devoid of care

Instead say...

“To respect his wishes, we will stop the breathing machine and use medicines to make his breathing comfortable,” or “If your heart stops, we will let you die peacefully.”
- Reframes the act of stopping into one of actively promoting the patient’s goals

Conversation Starters for Patients

“I know this is difficult but I would like to talk to you about something that is really important to me.”

“I care about you and want to tell you some things that I hope would make it easier for you if I couldn’t make decisions for myself.”

“It’s OK if you feel uncomfortable with this topic but please, just listen to me right now.”

“Please, do this for me.”

Review Your Wishes

If there’s a change in your family (divorce, death)
Pick an annual date to review like an anniversary, a family gathering or just before your annual check-up
When your health changes, especially a turn for the worse
If you’ve had to adjust to new limitations, make sure your directives still reflect your wishes
When you are dying
Helpful Resources

**Handouts:** American Academy of Family Physicians (AAFP) patient education website [www.familydoctor.org](http://www.familydoctor.org)

**Booklet:** Gone From My Sight, The Dying Experience by Barbara Karnes, [www.bkbooks.com](http://www.bkbooks.com)

**Video:** Arizona Attorney General, “Life Care Planning for Everyone” [www.azag.gov/life_care/LifeCarePlanningVideo.html](http://www.azag.gov/life_care/LifeCarePlanningVideo.html)

More Resources

**The Conversation Project**
[http://theconversationproject.org/](http://theconversationproject.org/)

**Hard Choices For Loving People, CPR, Artificial Feeding, Comfort Care, and the Patient with a Life Threatening Illness** by Hank Dunn
[www.hardchoices.com](http://www.hardchoices.com)

Life is pleasant. Death is peaceful. 
It's the transition that's troublesome.

— Isaac Asimov, American author and professor