Your Life Your Choices:
Straight Talk About Tough Issues

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Road Map

Making and communication health care decisions

Discuss how beliefs and values impact decisions

Explain common medical situations and treatment decisions
Who Makes These Decisions?
Affect on family when wishes are not communicated
What Happens When Family Members Disagree?

- Hurt Feelings
- Conflict
- Stress
- Confusion

You may not receive the care you would have wanted
How Can You Prevent or Minimize Disagreement?
Your Life Your Choices

1. The Basics
2. Thought-provoking exercises
3. Health conditions and treatments
4. Your health care preferences
5. How to talk about your wishes
Download the “Your Life, Your Choices: Planning for Future Medical Decisions” Workbook

AUGUST 31, 2009

Have questions about end-of-life care? Curious how to prepare a personalized living will?

Doctor Robert Pearlman, and others, wrote the Your Life, Your Choices under a Veterans Administration authorized grant, which was revised in 1997. The 52-page workbook is informative and easy to read, covering the issues important to end-of-life care decision making. Topics include:

- Why do you need to think about future health care decisions?
- If you couldn't speak for yourself, what would you want done for you?
- What situations and decisions do people commonly face?
- Your beliefs and values
- Choices about death and dying
- Talking about your wishes
- Legal and ethical issues of advance care planning

Download the Your Life, Your Choices Workbook

This document should only be used as a starting point, however. The decision making and living will development should be done in cooperation with those close to you, your family, doctor, clergy, lawyer, and others you see fit. Many states also offer state-specific living will documents for individuals in your location.

http://www.elderguru.com/download-the-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

When Should We Discuss Health Care Decisions?

When we’re healthy?

When we’re sick?

When we’re young?

When we’re “old?”
Choosing the Right Person

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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.
“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?”
And...

Assure them you won’t be offended if they decline

Reassure them they don’t have to be all-knowing

You’re giving explicit permission to make decisions, especially for situations you have not discussed

Have a family meeting so everyone who needs to have this information hears it in the same way
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
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”?
I believe it is always wrong to withhold (not start) treatments that could keep me alive.

I would like to have my pastor, priest, rabbi, or other spiritual advisor consulted...

I believe that controlling pain is very important, even if the pain medications might hasten my death.

I believe that it is acceptable to consider the financial burden of treatment on my loved ones when making health care decisions on my behalf.
Do you believe in miracles and want the doctors to keep you alive at all costs?

Would you want to be kept alive indefinitely because a new treatment might be developed?

What does hope mean to you?
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...
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?
Common Situations & Decisions
Do everything possible...
Pull the plug
Comfort is most important
Stop the breathing machine
I don’t want to be a vegetable...

Words Have Meaning
Dementia

Loss of memory and other mental functions

Progression is irreversible and worsens over time

**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
Coma

State of unconsciousness

Little to no movement or response to stimulation

Total care, including feeding tube

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

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

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
What will you do with the information?

Will it change your treatment plan?
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
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 lesson 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 Includes...

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
Risks of CPR

Sore or broken ribs

Punctured lungs

 Likely need mechanical ventilation

Rarely successful if other diagnoses present
   – Most people misunderstand the reality of the outcome of a CPR attempt
CPR on Television

Researchers watched 97 total episodes of *ER*, *Chicago Hope* and *Rescue 911*

- Observed 60 occurrences of CPR – mostly from trauma
  - Gun shots, MVA, near-drowning
- 65% occurred in children, teens and young adults

**Survival Rate**

- *ER* = 65%; *Chicago Hope* = 65%; *Rescue 911* = 100%!
- Many survived until discharge from hospital

**Portrayed as full recovery or death**

- No mention of prolonged suffering, severe neurological damage or undignified death

CPR = ICU
Doesn’t mean you will suffer
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

<table>
<thead>
<tr>
<th>PROS</th>
<th>CONS</th>
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<tr>
<td>• Painless but uncomfortable</td>
<td>• Cannot talk</td>
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<td>• Can allow the body to recover from an injury or short term illness</td>
<td>• Cannot eat</td>
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<td>• Totally dependent on others for all personal care</td>
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<td>• Usually restricted to bed</td>
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<td>• Suctioning of lungs to clear mucous</td>
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<td>• May prolong dying</td>
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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

So, WHAT Happened?

Use of artificial nutrition became widespread
Food = Heavy Symbolic Load
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 not improve comfort
• 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, will postpone death
Risks of Artificial Feeding

**Nasogastric or gastric tubes**
- Diarrhea
- Nausea
- Vomiting
- Esophageal perforation
- Infiltration of formula into lungs
- Increased need for suctioning

**Intravenous (fluids)**
- Infection, phlebitis (inflammation of a vein) and electrolyte imbalance
- Pulmonary or peripheral edema
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, Jacquelyn, PhD, RN. “Withholding nutrition at the end of life: Clinical and ethical issues.” Cleveland Clinic Journal of Medicine, 2003, 70(6), 548-552.
Eating for Comfort
Last Comment on Artificial Nutrition...

Withdrawing support is **MUCH MORE DIFFICULT** than withholding support.
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
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
<table>
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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)
Permanent Coma

This means you:

– Do not think, hear, or see
– Are not in pain
– Are confined to a bed because you cannot move
– Need 24-hour nursing care for bowel and bladder functions and skin care
– Will not substantially improve
Permanent Coma

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
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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

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### Severe Dementia

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Severe Stroke

This means you:

- Are able to think, but your ability to understand what is said to you and communicate with others is severely limited
- Have aches and pains that make you uncomfortable most of the time
- Are able to walk with a walker, but most of the time you get around in a wheelchair
- Need help with getting dressed, bathing, and bowel and bladder functions
Severe Stroke

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Terminal Illness

This means you:

– Have days when you drift in and out of awareness
– Have a lot of discomfort that requires medication
– Are in bed most of the time due to weakness
– Need help with getting dressed, bathing, and bowel and bladder functions
Terminal Illness

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Let’s take a moment and breathe
“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.”
Now That I’ve Started, What Do I Say?

Use this workbook as a foundation
• Choice of spokesperson and why
• Your beliefs about what makes life worth living and unbearable, and why
• Health conditions and how you feel about kept alive in certain situation
• Life sustaining treatments
• Your vision of a good death
• Organ donation
• Funeral arrangements
• Where your directives will be located, give copies
Suggestions

Use a story to help make your point

Remind the person of the reality that an accident can happen at any time

Thank the person for listening to you
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
Palliative Medicine

Medical *specialty* focused on comfort and quality of life

Identifies and honors the preferences of the patient and family through careful attention to their values, goals and priorities, as well as their cultural and spiritual perspectives

Focuses on living, through *meticulous attention* to symptom control and efforts to maximize functional status
Hospice

A comprehensive program of care

– Intense form of palliative care that operates under a distinct regulatory and licensing structure

– Supports an individual and family through the dying process

– Emphasis on quality of life, life-closure issues and relief of suffering

– Supports the family through the bereavement process
Must Physicians Honor Advance Directives?

Yes!
Great Questions to Ask

“Can I count on you to respect my wishes and contact my spokesperson if I’m unable to speak for myself?”

“What if you’re not the health care provider who’s there when I need care? How will the other health care providers know about my wishes.”
Keep your Health Care Providers Informed

Why is it important?

– To follow your wishes
– To interpret your directive how YOU intend and how you expect your spokesperson to carry out those wishes
– Answer questions about different health conditions, treatments and prognosis

DO NOT allow your directives to just be filed in your chart without reviewing them!
Advance Directives

Written document that specifies a person’s health care wishes in the event he or she is unable to make medical decisions

Types of Directives

- Medical or Healthcare Power of Attorney
- Living Will
- Mental Health Care Power of Attorney
- Prehospital Medical Care Directive (Orange Card)
Life Care Planning is an important task for all of us, whether young or old, healthy or facing challenges. There is a wealth of resources and important information. Arizona Attorneys General Office provides support and guidance to ensure that everyone is prepared for their future.
Document that allows an individual to designate a proxy (spokesperson) in the event the individual loses decision-making capacity
Only consult the MPOA if the person is not capable of decision-making

– Or specifically requests that the MPOA be involved
Letter to My Representative(s)

Letter explaining importance of accepting the responsibility to act as a Power of Attorney

Similar to a job description
Document that provides guidelines for patient wishes regarding life sustaining treatment under specific conditions:

- Persistent vegetative state
- Irreversible or incurable coma
- Terminal illness

Not a general will or a will and trust
Just because a person has a living will, it does NOT mean he or she is automatically a Do Not Resuscitate (DNR) code status.
Mental Health Care Power of Attorney

Document that allows an individual to designate a proxy (spokesperson) for mental health-related decisions such as the authority to admit to a behavioral health facility.
The Living Will, Medical Power of Attorney and Mental Health Care Power of Attorney do not need to be notarized, only witnessed.

The witness cannot be someone who is directly involved in providing medical care to the person, who is related by blood, marriage or adoption or entitled to any part of the person’s estate.
Prehospital Medical Care Directive, the “Orange Card”

Document that directs the withholding of CPR, including cardiac compression, endotracheal intubation and other advanced airway management, artificial ventilation, defibrillation, administration of advanced cardiac life support drugs and any related emergency medical procedures
DNR Form Must Be on Orange Paper
Who Signs the Orange Card?

If possible, the individual

If not, the Power of Attorney “POA”

If no POA, the surrogate

Physician OR a licensed health care provider along with a witness
I’ve been asked several times...
In some situations, returning to the hospital will not result in a different or better outcome and may be more burdensome.

Discussions of DNH may be met with sighs of relief.

“You mean I don’t HAVE to go back to the hospital?”
How Can My Physician Help?

WRITE ORDERS
Physician Orders for Life-Sustaining Treatment (POLST)

An approach to improving end-of-life care in the United States, encouraging doctors to speak with patients and create specific medical orders to be honored by health care workers during a medical crisis.
Other Resources
Arizona Donor Registry

Pancreas, kidneys, liver, lungs, intestines, tissues, skin and corneas

One donor can help up to 50 people

www.azdonorregistry.org/registernow/registration.aspx
1-800-943-6667
Anatomical Donation

Donation of body for research on diseases such as cancer, arthritis, heart disease, MS, spinal injury and diabetes
Anatomical Donation Organizations

**LifeLegacy Foundation** - nonprofit research organ and tissue bank accredited by the American Association of Tissue Banks

[www.lifelegacy.org](http://www.lifelegacy.org)

**Science Care** is an option which is for-profit but also accredited

[www.sciencecare.com](http://www.sciencecare.com)
Donation Organizations cont.

Biological Resource Center - willed body to science program

http://www.brcil.org

International Institute for the Advancement of Medicine (IIAM)

602-287-9423 or 800-806-4426

www.iiam.org
Funeral Consumer Alliances

Southern and Central Arizona are joining services

Southern Arizona, (520) 721-0230

Central Arizona, (480-929-9659)
http://www.fcaofcentralaz.org/

Memorial Society of Prescott (serves Northern Arizona), (928-778-3000)
Funeral Consumer Alliance of Southern Arizona

- Operated by volunteers
- One-time membership Fee $40.00
- Annual renewal $10.00
- Choose from three packages
  - Direct Cremation (approx $760.00)
  - Direct Burial (approx $1225.00)
  - Economical Funeral (approx $1615.00)
The Arizona Advance Directive Registry

Created in May 2004 by the Arizona State Legislature

Database for the storage of advance directives
  Healthcare Power of Attorney
  Living Will
  Mental Healthcare Power of Attorney
  Your Life Your Choices workbook
  *Do Not Resuscitate forms cannot be stored*

Must be an Arizona resident with a current AZ home address

[www.azsos.gov/adv_dir/](http://www.azsos.gov/adv_dir/)
The Wallet Card

A wallet card with a password is issued once advance directives have been verified.
Write It Down

Events surrounding these decisions can be stressful and filled with strong emotions

- Advance directive documents
- Your Life Your Choices workbook
- A letter
- Audio or video tape
Make multiple copies
– Give to all family members

Bring copies to all medical appointments
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
**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)

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

— Isaac Asimov, American author and professor
Thank you for your time
Paige