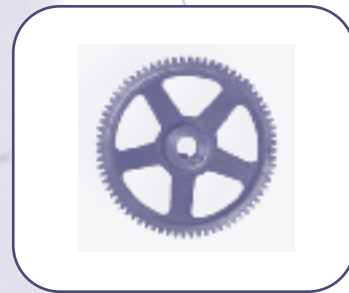


# TOOL KIT *for* HEALTH CARE ADVANCE PLANNING



# Tool Kit For Health Care Advance Planning

## INTRODUCTION

If you are looking at this Tool Kit, you are either thinking of making a health care advance directive (such as a Living Will or Special Power of Attorney for Health Care), or you may have already signed one. In either case, you should be aware that having a written advance directive by itself does not ensure that your wishes will be understood and respected. Studies have shown that standard advance directive forms do little to influence end-of-life decisions without: 1) informed, thoughtful reflection about your wishes and values, and 2) personal communication between you and your likely decision-makers before a crisis occurs.

## WHY A TOOL KIT?

Good advance planning for health care decisions is a continuing conversation – about values, priorities, the meaning of one's life, and quality of life. To help you in this process, this Tool Kit contains a variety of self-help worksheets, suggestions, and resources. There are 10 Tools in all, each clearly labeled and user-friendly.

### Tool Kit Contents:

- TOOL #1 How To Select Your Health Care Agent or Proxy
- TOOL #2 Are Some Conditions Worse Than Death?
- TOOL #3 How Do You Weigh Odds of Survival?
- TOOL #4 Personal Priorities and Spiritual Values Important To Your Medical Decisions
- TOOL #5 After Death Decisions To Think About Now
- TOOL #6 Conversation Scripts: Getting Past the Resistance
- TOOL #7 "Proxy IQ Test" For Family & Physician
- TOOL #8 What To Do After Signing Your Health Care Advance Directive
- TOOL #9 Guide for Health Care Proxies
- TOOL #10 Resources: Utah Forms

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# How to Select Your Health Care Agent or Proxy



Name & Date \_\_\_\_\_

## WHY DESIGNATE A HEALTH CARE PROXY?

Physicians who care for dying patients want to provide the care that each individual patient would want at that time. Often, patients' wishes change as an illness progresses. Physicians, who want good, current, and pertinent information about the patient's preferences to drive end-of-life decisions, prefer to follow instructions from a decision maker who has been designated by the patient, rather than relying on a living will. This designated decision maker is typically called a health care agent, representative, attorney-in-fact, or proxy.

Utah law reflects this preference for a health care proxy. If the directions of a patient's health care proxy differ from a living will, the law directs the physician to follow the proxy's instructions. Therefore, it is important to choose a health care proxy who will know your wishes, be able to communicate your wishes to healthcare providers, and advocate for you when you cannot advocate for yourself. Tool #1 will help you to choose this agent.

You may use Utah's Special Power of Attorney form, Tool #10, Page 4, to designate your healthcare proxy. It is usually best to name one person to serve as proxy, with at least one back-up person, in case the first person is not available when needed.

## WHO CAN'T BE A PROXY?

Utah law prohibits anyone under age 18 from being a proxy.

## WHO SHOULDN'T BE A PROXY?

Other states prohibit the following people from being proxies. It is usually best to avoid naming one of these people as your proxy, unless he or she is related to you.

- Your health care provider, including the owner or operator of a health or residential or community care facility serving you -- unless this person is your spouse or close relative.
- An employee of your health care provider -- unless this person is your spouse or close relative.

## WHAT TO DO AFTER YOU CHOOSE A HEALTH CARE PROXY?

- Talk to your proxy about the qualifications on the first page of this worksheet.
- Ask permission to name him or her as your proxy.
- Discuss your health care wishes and values and fears.
- Make sure your proxy gets an original copy of your advance directive.
- Tell family members and close friends who you've selected as your proxy.

*Compare up to three people with this tool. The persons best suited to be your Health Care Agents or Proxies will rate well on these qualifications.*

Name #1:		
Name #2:		
	Name #3:	
		1. Meets the legal criteria in your state for acting as agent or proxy or representative. (This is a must! See previous page.)
		2. Would be willing to speak on your behalf.
		3. Would be able to act on your wishes and separate his/her own feelings from yours.
		4. Lives close by or could travel to be at your side if needed.
		5. Knows you well and understands what's important to you.
		6. Could handle the responsibility.
		7. Will talk with you now about sensitive issues and will listen to your wishes.
		8. Will likely be available long into the future.
		9. Would be able to handle conflicting opinions between family members, friends, and medical personnel.
		10. Can be a strong advocate in the face of an unresponsive doctor or institution.

This worksheet adapted by the American Bar Association's Commission on Legal Problems of the Elderly from R. Pearlman, et. al., *Your Life Your Choices – Planning for Future Medical Decisions: How to Prepare a Personalized Living Will*, Veterans Administration Medical Center, Seattle, Washington.

# Are Some Conditions Worse than Death?

Name & Date \_\_\_\_\_

This worksheet helps you to think about situations in which you would not want medical treatments that are intended to prolong your life. Many treatments can keep you alive, even if there is no chance that they will cure the underlying illness. For the situations described below, consider if you would definitely want, or definitely do not want, life-prolonging treatment.

*Directions: Circle the number from 1 to 5 that best indicates the strength and direction of your desire. If you wish, you can add additional thoughts on the Comment lines.*

- 1 -- Definitely want treatments that might keep you alive.
- 2 -- Probably would want treatments that might keep you alive.
- 3 -- Unsure of what you want.
- 4 -- Probably would NOT want treatments that might keep you alive.
- 5 -- Definitely do NOT want treatments that might keep you alive.

What if you . . .	Definitely Want Treatment	←→	Definitely Do Not Want Treatment		
a. Can no longer walk but get around in a wheelchair.	1	2	3	4	5
Comment _____					
b. Can no longer get outside. You spend all day at home.	1	2	3	4	5
Comment _____					
c. Can no longer contribute to your family's well-being.	1	2	3	4	5
Comment _____					
d. Rely on medications that may cause some side effects to manage pain.	1	2	3	4	5
Comment _____					
e. Experience nausea, diarrhea, fatigue some of the time.	1	2	3	4	5
Comment _____					

continued on next page

Definitely  
Want  
Treatment



Definitely  
Do Not Want  
Treatment

## What if you . . .

f. Require a feeding tube to keep you alive. 1 2 3 4 5

Comment \_\_\_\_\_

g. Require a kidney dialysis machine to keep you alive. 1 2 3 4 5

Comment \_\_\_\_\_

h. Require a breathing machine to keep you alive. 1 2 3 4 5

Comment \_\_\_\_\_

i. Need someone to take care of you 24 hours a day. 1 2 3 4 5

Comment \_\_\_\_\_

j. Can no longer control your bladder. 1 2 3 4 5

Comment \_\_\_\_\_

k. Can no longer control your bowels. 1 2 3 4 5

Comment \_\_\_\_\_

l. Live in a nursing home. 1 2 3 4 5

Comment \_\_\_\_\_

m. Can no longer think or talk clearly 1 2 3 4 5

Comment \_\_\_\_\_

n. Can no longer recognize family or friends. 1 2 3 4 5

Comment \_\_\_\_\_

o. Other: 1 2 3 4 5

Explain \_\_\_\_\_

This worksheet adapted by the American Bar Association's Commission on Legal Problems of the Elderly from R. Pearlman, et. al., *Your Life Your Choices – Planning for Future Medical Decisions: How to Prepare a Personalized Living Will*, Veterans Administration Medical Center, Seattle, Washington.

# How Do You Weigh Odds of Survival?

Name & Date \_\_\_\_\_

People evaluate the pros and cons of medical treatments in very personal ways. This explains why some people choose a treatment and others reject it. A big question is, how much would you be willing to endure if the chance of regaining your current health was high? What if the chance was low? Answer the questions below to assess your willingness to take such risks.

Imagine that you are seriously ill. The doctors are recommending treatment for your illness, but the treatment may have side effects, such as pain, nausea, vomiting, or weakness. While pain and other side effects can usually be managed effectively, in very few cases, the side effects are difficult to manage. You may also experience social isolation.

Question: Would you agree to the treatment if the chance that you would regain your current health was: (Circle one answer for each)

High (over 80%)	Yes	Not sure	No
Moderate (50%)	Yes	Not sure	No
Low (20%)	Yes	Not sure	No
Very low (less than 2%)	Yes	Not sure	No

This worksheet adapted by the American Bar Association's Commission on Legal Problems of the Elderly from R. Pearlman, et. al., *Your Life Your Choices – Planning for Future Medical Decisions: How to Prepare a Personalized Living Will*, Veterans Administration Medical Center, Seattle, Washington.

# Personal Priorities & Spiritual Values Important to Your Medical Decisions

Name & Date \_\_\_\_\_

People have personal priorities and spiritual beliefs that affect their medical decisions. This is especially true at the end of life with regard to the use of life-sustaining treatments. To make your values and beliefs more clear, consider answering the questions below. Use more paper if you need more space.

## PERSONAL PRIORITIES/CONCERNS

1. What do you most value about your physical or mental well-being? For example, do you most love to be outdoors? To be able to read or listen to music? To be aware of your surroundings and who is with you? Seeing, tasting, touching?
2. What are your fears regarding the end of life?
3. Would you want to be sedated if it were necessary to control your pain? Note, however, that in more than 95% of patients, pain can be managed effectively without major side effects. It is extremely unlikely – less than 2% chance – that you would require sedation to manage pain.
4. Would you want to have a hospice team or other palliative care (i.e., comfort care) available to you?
5. If you could plan it today, what would the last day or week of your life be like?  
For example ...
  - Where would you be? What would your environment be like?
  - Who would be present?
  - What would you be doing?
  - What would you eat if you could eat?
  - What would be your final words or last acts?

6. Are there people to whom you want to write a letter or for whom you want to prepare a taped message, perhaps marked for opening at a future time?
  
7. How do you want to be remembered? (If you wrote your own epitaph or obituary, what would it say?)
  
8. What are your wishes for a memorial service – for example, the songs or readings you want, or the people you hope will participate?

### **SPIRITUAL/RELIGIOUS MATTERS OF IMPORTANCE TO YOU**

9. How would you describe your spiritual or religious life?
  
10. What gives your life its purpose and meaning?
  
11. What is important for others to know about the spiritual or religious part of your life?
  
12. What do you need for comfort and support as you journey near death? For example, to pray with a member of the clergy? To have others pray for you? To be read to from spiritual or religious texts? To have music playing in your room? To be held?

This Worksheet adapted by the American Bar Association's Commission on Legal Problems of the Elderly from *Caring Conversations*, a workbook published by the Midwest Bioethics Center, 1021-1025 Jefferson Street, Kansas City, MO 64105



# After Death Decisions To Think About Now

Name & Date \_\_\_\_\_

After the death of a loved one, family and friends are often left with some tough decisions. You can help ease the pain and anxiety by making your wishes -- about burial, autopsy and organ donation -- clear in advance.

## ORGAN AND TISSUE DONATION

### DID YOU KNOW?

More than 68,000 patients are on the national organ transplant waiting list. Each day, 13 of them will die because the organs they need have not been donated. Every 16 minutes, a new name will be added to that waiting list.

**Organs** you can donate: Heart, Kidneys, Pancreas, Lungs, Liver, Intestines.

**Tissue** you can donate: Cornea, Skin, Bone marrow, Heart valves, Connective tissue.

To be transplanted, organs must receive blood until they are removed from the body of the donor. Therefore, it may be necessary to place the donor on a breathing machine temporarily or provide other organ-sustaining treatment.

If you are older or seriously ill, you may or may not have organs or tissue suitable for transplant. Doctors evaluate the options at or near the time of death.

The body of an organ donor can still be shown and buried after death.

1. Do you want to donate viable **ORGANS** for transplant? (Circle one)

- Yes
- Not sure
- No

If Yes, check one:

- I will donate any organs.
- Just the following:

\_\_\_\_\_

2. Do you want to donate viable **TISSUES** for transplant? (Circle one)

- Yes
- Not sure
- No

If Yes, check one:

- I will donate any tissue.
- Just the following:

\_\_\_\_\_

**Attention!** If you circled Yes for either of the above, be sure to write this into your health care Advance Directive. You may also fill out an organ donor card or register as an organ donor when you renew your driver's license. **Tell your proxy and loved ones.** Make sure they will support your wishes. Even with an organ donor card, hospitals will ask your proxy or family to sign a consent form.

3. If you do not donate organs or tissue, you may choose to donate your **WHOLE BODY** for medical research or education. Medical schools need to study bodies to gain greater understanding of disease mechanisms in humans. Note that total body donation is not an option if you choose to be an organ or tissue donor.

Yes                      Not Sure                      No

If you circle "Yes," you may contact the University of Utah Body Donor Program at 801-581-6728.

4. Would you agree to an autopsy? (Autopsies, done after death, are used for diagnostic and research purposes. The body can still be shown and buried.)

Yes                      Not sure                      No

## BURIAL ARRANGEMENTS

5. I would prefer to be: (circle one)

Buried                      Cremated                      No Preference

6. I would like my remains to be placed:

7. Other preferences:

# Conversation Scripts: Getting Past the Resistance

## WHY TALK ABOUT MEDICAL PREFERENCES IN ADVANCE?

Communication is the single most important step in health care planning. Talk about your wishes with the people who may be called upon to speak or decide for you. Why?

1. No matter what your advance directive says, others will not fully understand your wishes. The more thoroughly you communicate, the easier it will be for everyone to respect your wishes.
2. It will help you think about what you want. Others will ask you questions or tell you things that will make you think about your wishes in another way.
3. It will help your loved ones make difficult decisions with less pain, doubt, and anxiety.
4. It may save money. Sometimes families continue medical treatments long past the point where they are helpful, simply because they are unsure what their loved one would have wanted. This is emotionally and financially costly ... and unnecessary.
5. It may even bring your family closer together.

## STARTING THE DISCUSSION

There's no "right" way to start. Nor is there a "right" time. Nor does the discussion necessarily have to be somber and mournful. Here are some suggestions for getting started:

- Start with a story of someone else's experience:

*"Do you remember what happened to so-and-so and what his family went through? I don't want you to have to go through that with me. That's why I want to talk about this now, while we can."*

*"Neither Richard Nixon nor Jackie Kennedy was placed on life support. I wonder if they had Living Wills and made what they wanted clear in advance."*

- Blame it on your attorney:

*"Mr. Darrow, my lawyer, says that before I complete some legal documents, I need to talk over with you some plans about end-of-life medical care."*

- Use the worksheets provided in this packet to guide the discussion. A variety of other workbooks are also available.

- Use a letter, tape, or video recording as a starting point. At first, it may be easier for people to hear what you have to say if you are not there. Afterwards they may be more ready to sit down and talk with you.

### RESISTANCE TO THE DISCUSSION IS COMMON, FOR EXAMPLE ...

*"Mom, I don't see what good it does to talk about such things. It's all in God's hands anyway."*

*"Dad, I already know you don't want any heroic measures if things are really bad. There's nothing more we need to discuss about it. We'll do the right thing if the situation arises."*

*"I just can't talk about this. It's too painful, and talking about it just makes it more likely that it will happen."*

### IN RESPONSE ...

- Be firm and straightforward.

*"I know this makes you feel uncomfortable, but I need you to listen, to hear what I have to say. It's very important to me."*

*"Yes, death is in God's hands, but how we live until that moment is in our hands, and that's what I need to talk to you about."*

*"If it is too overwhelming for you right now, I understand. But let's make an appointment for a specific time to sit down together to discuss this. All right?"*

- Point out the possible consequences of not talking now.

*"If we don't talk about this now, we could both end up in a situation that is even more uncomfortable. I'd really like to avoid that if I could."*

- Ask someone to be your spokesperson.

If you are able to connect well with one family member or friend, ask this person to initiate and lead the discussion with other family members or your doctor. This may make your job of explaining, clarifying, and answering questions easier.

This worksheet adapted by the American Bar Association's Commission on Legal Problems of the Elderly from R. Pearlman, et. al., *Your Life Your Choices – Planning for Future Medical Decisions: How to Prepare a Personalized Living Will*, Veterans Administration Medical Center, Seattle, Washington.



# "Proxy IQ Test" For Family or Physician

How well does your family, proxy, or doctor know your health care wishes? This short test can give you some sense of how well you have communicated your wishes to them. Consider this a tool to promote better conversation and understanding.

## INSTRUCTIONS:

### Step 1:

Answer the 10 questions using the Personal Medical Preferences test which follows.

### Step 2:

Then, ask your health care proxy, family member, or close friend to complete the Proxy Understanding of Your Personal Medical Preferences test. The questions are the same. Don't reveal your answers until after they take the test. They should answer the questions in the way they think you would answer.  
(Try the same test with your doctor, too.)

### Step 3:

GRADING – Count one point for each question on which you and your proxy (or you and your doctor) gave the same answer. Their "Proxy IQ" is rated as follows:

Points	Grade
10	Superior – You are doing a great job communicating!
8 – 9	Good – Need some fine tuning!
6 – 7	Fair – More discussion needed.
5 or below	Poor – You have a lot of talking to do!

*The tests are on the following pages ...*

# Proxy IQ Test

## Step 1: Personal Medical Preferences

Complete this questionnaire by yourself.

1. Imagine that you had Alzheimer's Disease and it had progressed to the point where you could not recognize or converse with your loved ones. When spoon-feeding was no longer possible, would you want to be fed by a tube into your stomach?
- Yes
  - No
  - I am uncertain

2. Which of the following do you fear most near the end of life?
- Being in pain
  - Losing the ability to think
  - Being a financial burden on loved ones

3. Imagine that ...
- You are now seriously ill, and doctors are recommending chemotherapy, and
  - This chemotherapy may have side effects, such as nausea, vomiting, and weakness that could last for two to three months, though a skilled palliative care physician can usually effectively manage most of these side effects.

Would you be willing to endure the side effects if the chance of regaining your current health was less than 2 percent?

- Yes
  - No
  - I am uncertain
4. In the same scenario, suppose that your condition is clearly terminal, but the chemotherapy might give you six additional months of life. Would you want the chemotherapy described above?
- Yes
  - No
  - I am uncertain
5. If you were terminally ill with a condition that caused much pain, would you want to be sedated, even to the point of unconsciousness, if it were necessary to control your pain? Note, however, that sedation for pain management is necessary for fewer than 2% of all patients at the end of life.
- Yes
  - No
  - I am uncertain

continued on next page

6. Imagine that ...

- You have moderate dementia causing mental confusion. About half the time, you recognize and interact with friends and loved ones on a simple level.
- You also have circulatory problems, which resulted in one leg being amputated because it developed gangrene. Now, the other leg develops gangrene and the doctor recommends amputation because the condition could be fatal.

Would you want the operation?

- a. Yes
- b. No
- c. I am uncertain

7. Is it more important for you to: (a) have your specific treatment preferences followed at the end of life even if family members or friends disagree, or (b) have family and friends all in agreement and comfortable with whatever decision is made?

- a. Have specific preferences followed, even if there is disagreement
- b. Have family and friends all in agreement
- c. I am uncertain

8. Imagine that ...

- You are physically frail and you need help with most routine daily activities – dressing, bathing, eating, and going to the toilet
- You live in a nursing home
- Your mind is fairly clear and capable most of the time, and
- You have had pneumonia or other lung infections four times in the last year. Each time you had to be hospitalized for several days and given antibiotics through an IV tube.

The next time you get pneumonia, do you want aggressive antibiotic treatment again or just comfort care only until death comes?

- a. Antibiotic treatment
- b. Comfort care
- c. I am uncertain

9. Imagine that ...

- You are in a permanent coma, and
- You are dependent on a tube inserted into your stomach (food and water).

Would it be important to you that decisions about your treatment be guided by particular religious beliefs or spiritual values that you hold?

- a. Yes
- b. No
- c. I am uncertain

10. If your heart, kidneys, pancreas, lungs and liver could all be used in transplant operations to save lives, would you want to donate them at death?

- a. Yes
- b. No
- c. I am uncertain

- END -

# Proxy IQ Test

## Step 2: Proxy Understanding of Your Personal Medical Preferences

To be completed by your named health care proxy, family member, close friend or physician.

*Instructions: Answer the following questions in the way you think "N" (name: \_\_\_\_\_) would answer.*

1. Imagine that N had Alzheimer's Disease and had progressed to the point where he/she could not recognize or converse with loved ones. When spoon-feeding was no longer possible, would he/she want to be fed by the insertion of a tube into the stomach?
  - a. Yes
  - b. No
  - c. N would be uncertain
2. Which of the following do you think N fears most near the end of life?
  - a. Being in pain
  - b. Losing the ability to think
  - c. Being a financial burden on loved ones
3. Imagine that N ...
  - Is now seriously ill, and doctors are recommending chemotherapy, and
  - This chemotherapy may have side effects, such as nausea, vomiting, and weakness that could last for two to three months, though a skilled palliative care physician can usually effectively manage most of these side effects.Would N be willing to endure the side effects if the chance of regaining his/her current health was less than 2 percent?
  - a. Yes
  - b. No
  - c. N would be uncertain
4. In the same scenario, suppose that his/her condition is clearly terminal, but the chemotherapy might give six additional months of life. Would N want the chemotherapy described above?
  - a. Yes
  - b. No
  - c. N would be uncertain
5. If N were terminally ill with a condition that caused much pain, would N want to be sedated, even to the point of unconsciousness, if it were necessary to control the pain?
  - a. Yes
  - b. No
  - c. N would be uncertain

continued on next page



6. Imagine that N ...

- Has moderate dementia causing mental confusion. About half the time, N recognizes and interacts with friends and loved ones on a simple level.
- Also has circulatory problems, which resulted in one leg being amputated because it developed gangrene. Now, the other leg develops gangrene and the doctor recommends amputation because the condition could be fatal.

Would N want the operation?

- a. Yes
- b. No
- c. N would be uncertain

7. Is it more important for N to: (a) have his/her specific treatment preferences followed at the end of life even if family members or friends disagree, or (b) have family and friends all in agreement and comfortable with whatever decision is made?

- a. Have specific preferences followed, even if there is disagreement
- b. Have family and friends all in agreement
- c. N would be uncertain

8. Imagine that N ...

- Is physically frail and needs help with most routine daily activities – dressing, bathing, eating, and going to the toilet
- Lives in a nursing home
- Mentally, is fairly clear and capable most of the time, and
- Has had pneumonia or other lung infections four times in the last year. Each time N had to be hospitalized for several days and given antibiotics through an IV tube.

The next time N gets pneumonia, do you think he/she would want aggressive antibiotic treatment again or just comfort care until death comes?

- a. Antibiotic treatment
- b. Comfort care
- c. N would be uncertain

9. Imagine that N ...

- Is in a permanent coma, and
- Is dependent on a tube inserted into the stomach for nutrition and hydration, (food and water).

Would it be important to N that decisions about N's treatment be guided by particular religious beliefs or spiritual values held by N ?

- a. Yes
- b. No
- c. N would be uncertain

10. If N's heart, kidneys, pancreas, lungs, and liver could all be used in transplant operations to save lives, would he/she want to donate them at death?

- a. Yes
- b. No
- c. N would be uncertain

# What To Do After Signing Your Health Care Advance Directive

## GOOD ADVANCE PLANNING IS A CONTINUING CONVERSATION

Advance planning for health care is always a work in progress. That's because circumstances change, and lives change. One's values and priorities even change. As a sage remarked, "The world looks different when you're horizontal rather than vertical."

## WHAT ARE ADVANCE DIRECTIVES?

Documents that instruct your health care provider either what you want done in certain circumstances, or who should make decisions for you if you cannot make or communicate decisions about your health care, are called advance directives.

Utah law includes three advance directive forms: Directive to Physicians and Providers of Medical Services (Living Will), Directive for Medical Services After Injury or Illness Is Incurred (Medical Treatment Plan), and Special Power of Attorney for Healthcare (which designates your health care agent or proxy). These forms are located in Tool 10.

Utah Department of Health Regulations also supports the use of a Physician Order for Life-Sustaining Treatment form. The POLST form is not an advanced directive, it translates your living will and other advanced directives into a physician order.

Completing these forms will help to communicate your wishes to your health care providers. But you do not need a living will to tell your doctor that you do not want life-sustaining treatments if you can speak for yourself. Your direct instructions to your doctor should be honored, even if family members or your health care proxy disagree with your instructions.

### a. Living Will

In Utah, a Living Will allows you to indicate in writing what care you wish to receive if you have or develop a terminal condition or if you fall into a persistent vegetative state and cannot make decisions. If you have signed a Special Power of Attorney for Healthcare and the health-care proxy disagrees with the wishes expressed in the living will, the physicians must do what the healthcare proxy directs.

### b. Special Power of Attorney for Healthcare

A Special Power of Attorney is a written statement that gives legal authority to another person to make healthcare decisions for you if you cannot make your own decisions due to an illness or injury. This person is called a "health care proxy." You can identify the person you want to make your healthcare decisions by using a Special Power of Attorney form. The form must be signed before a notary public.

### c. Medical Treatment Plan

A Medical Treatment Plan, also referred to as a "Directive for Medical Services After Injury or Illness," allows you or your proxy and your physician to record a plan for care that is binding on physicians and other medical care providers. The Medical Treatment Plan is completed only after you already have a serious illness or disease, or if you are considering an operation or other

medical procedure that could result in substantial impairment or death. The law specifically permits Medical Treatment Plans for those over 18 years of age.

#### d. **Physician Order for Life-Sustaining Treatment Form (POLST)**

The POLST form allows you or your proxy to record end-of-life care preferences in a form that asks about specific treatments. Your physician must sign the form. Once you complete the form, hospitals, nursing homes and paramedics must honor the form. The POLST form is not a living will. It is a physician order.

### **FIVE TIMES TO RE-EXAMINE YOUR HEALTH CARE WISHES**

1. Before each annual physical exam.
2. At the start of each decade of your life.
3. After any major life change – such as a birth in the family, marriage, divorce, re-marriage, and especially after the death of a loved one.
4. After any major medical change – such as being diagnosed with a serious disease or terminal illness. Or if such conditions worsen.
5. After losing your ability to live independently.

### **IF YOUR WISHES CHANGE ...**

You can make a new advance directive such as a Living Will or Special Power of Attorney if your wishes change.

To revoke an advance directive, you may destroy the old one, write, "revoked" across the old one, write a new one, or tell someone that you want to revoke it. If you tell someone that you want to revoke the advance directive, you should do so in the presence of an adult witness who should then sign and date a written statement confirming that you have revoked the advance directive. If you change your advance directives, it is important to notify everyone who has a copy of your old forms.

### **WHAT TO DO WITH YOUR ADVANCE DIRECTIVE OR POLST FORM**

1. Keep the original copy of your health care advance directive and these work sheets or other notes where they can be easily found.
2. Give your chosen proxy a copy of the directive plus any worksheets or notes. Make sure your

continued on next page

proxy knows where to find the original. Also, give copies to other family members or friends who may have to make a medical decision for you. Your wishes are most likely to be honored if all family members agree on the plan of care.

3. Give your doctor a copy of your directive. Make certain it is put in your medical record. Make sure your doctor will support your wishes. If your doctor has objections, you need to work them out or find another doctor.
4. Carry an advance directive wallet card with you.
5. If entering a hospital or nursing home, take a copy of your directive with you and ask that it be placed in your medical record.
6. Some organizations offer to register advance directives electronically and enable health care institutions to access them electronically. Some churches and synagogues keep advance directives on file for members. You may wish to consider such a service.

### IF YOU DON'T WANT EMERGENCY CPR, ONE MORE STEP ...

If you are living at home, in a nursing home, or in assisted living and you do not want emergency CPR or other aggressive or life-sustaining treatments, complete the POLST form (Tool 10 page 5-6) with your health care provider. Once the form is completed, make sure that it would be available to emergency personnel. For example, leave it in an envelope on the wall over your bed.

# Guide for Health Care Proxies

If you are in a position to make medical decisions for someone else, this guide is for you. If you have been named in someone's medical power of attorney or other advance directive, then you may be referred to as the person's proxy, agent, attorney-in-fact, surrogate, or representative. These are all essentially the same job. Even if you have not been named, you may be called upon to participate in medical decisions for close family or friends who are in a medical crisis and cannot speak for themselves.

## EXACTLY WHAT ARE YOUR DUTIES AS A PROXY OR AGENT?

Your duties depend on what the person's advance directive says and upon state law. You have to read the advance directive and ask about state law. Your duties begin when the individual loses the ability to make health care decisions on his or her own.

In general, you will have authority to make any and all decisions a patient would make for him or herself, if able. This includes:

1. Receiving the same medical information the individual would receive.
2. Conferring with the medical team.
3. Reviewing the medical chart.
4. Asking questions and getting explanations.
5. Discussing treatment options.
6. Requesting consultations and second opinions.
7. Consenting to or refusing medical tests or treatments, including life-sustaining treatment.
8. Authorizing a transfer to another physician or institution, including another type of facility (such as a hospital or skilled nursing home).

## HOW TO MAKE MEDICAL DECISIONS

The toughest decision may concern beginning or stopping life-sustaining treatments. In each life there may come a time when the patient's condition has deteriorated and it is clear that he or she will not get better. Family members or doctors may then question the value of life-sustaining treatments that seem to prolong the process of dying. Rather than thinking of this as depriving your loved one of necessary treatment, you may be protecting him or her from unnecessary pain and suffering. Many people say they do not want to die slowly, hooked up to machines or fed artificially through tubes. What does your loved one think? Use the steps on the next page to help you decide.

# Steps For A Proxy To Follow

Deciding for a loved one (whom we will call Mary)



1. Find out the medical facts. This requires talking to the doctors and getting a complete picture of the situation. Questions you can use:

- What is the name of Mary's condition?
- If you don't know exactly what's wrong, what are the possibilities?
- Are tests needed to know more? Will the outcome of more testing make any difference in how you treat her, or in how she wants to be treated? (If not, why do the test?)
- What is the purpose of each test? Do the tests have risks or discomfort associated with them?
- Is the information you need worth the risk or discomfort of the test?"
- What is her condition doing to her now?
- How do you explain her symptoms?
- What usually happens with this disease?
- What do you think will be the likely course of this disease or condition?
- How severe or advanced is her case?

2. Find out the options. Make sure the physician describes the risks and benefits of each option. You may want to ask:

- How will this option make Mary improve or feel better?
- What is the success rate statistically? What is success?
- Can this procedure be done on a trial basis and then reevaluated? What is an appropriate amount of time for a trial? Are you willing to stop it after an agreed-upon trial?
- What defines "success" for this option? (It may not be what Mary would consider a success.)
- What will it mean to her quality of life?
- If she is to die, how might it affect the circumstances of her death? (For example, will it likely require hospitalization instead of home care?)
- What are the possible side effects?
- What option do you recommend, and why?

3. Figure out how Mary would decide if she knew all the facts and options. You have three possible approaches to making the decision:

- One - If you know preferences, follow them.
- Two - If you do not know Mary's wishes for the specific decision at hand, but you have evidence of what she might want, you can try to figure out how she would decide. This is called substituted judgment, and it requires you imagining yourself in the patient's position. Consider her values, religious beliefs, past decisions, and past statements she has made. The aim is to choose as Mary would probably choose, even if it were not what you would choose for yourself.
- Three - If you have very little or no knowledge of what Mary would want, then you and the doctors will have to make a decision based on what a reasonable person in the same situation would decide. This is called making decisions in the patient's best interest. Evaluate the benefits and burdens of the proposed treatment. For example, will the treatment cause Mary pain or suffering? Is it likely to make Mary better?

**THINGS A PROXY CAN DO TO MAKE DECISIONS EASIER**

- DO prepare in advance with the individual.** Learn what is important to your loved one in making health care decisions. Do this before he or she loses the ability to decide. Talk about beliefs and values regarding living, and dying. Talk about spiritual beliefs.
- DO make yourself and your role known to the medical staff.** Make sure the advance directive is in the medical chart. Keep a copy yourself, handy, to show to people involved in the individual's medical care. Keep in touch with these people.
- DO stay informed about the person's condition as it changes.** Medical conditions change. Staff at the hospital change. Identify the person who can best keep you informed of the individual's condition. Stay involved and be flexible.
- DO keep the family informed, if appropriate.** You may have the legal authority to make medical decisions even if family members disagree. However most proxies are more comfortable if there is agreement among loved ones. Good communication can foster consensus. But you may also need help in resolving family disagreements. Ask for the facility's patient representative or ombudsman, social worker, clergy or spiritual advisor. Or ask for the ethics committee or ethics consultant.
- DO advocate on the patient's behalf and assert yourself with the medical team, if necessary.** Some medical people may not be as comfortable as others with your involvement. You may disagree with the doctor's recommendations. It is hard to disagree with medical professionals and institutional authorities. Be tactful and assertive. If their resistance becomes a problem, or if you feel you are not being heard, ask for help. Ask for help from the facility's patient representative or ombudsman, social worker, clergy or spiritual advisor, ethics committee or ethics consultant.

Adapted by the American Bar Association's Commission on Legal Problems of the Elderly from:  
*Making Health Care Decisions for Others: A Guide To Being A Health Care Proxy or Surrogate*,  
by The Division of Bioethics, Montefiore Medical Center, Albert Einstein College of Medicine, Bronx, New York



Effective January 2008, The Utah Commission on Aging web site has copies of the new forms, instructions and provider training documents available for download at [http://www.aging.utah.edu/utah\\_coa/directives](http://www.aging.utah.edu/utah_coa/directives).

Previous outdated Advanced Directive pages have been removed intentionally from this 2005 publication.

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