Consumer's Tool Kit for Health Care **Advance Planning**

Second Edition

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Consumer's 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 durable power of attorney for health care), or you may have already signed one. In either case, you should be aware that just 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, in reality, 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. The tool kit does not create a formal advance directive for you. Instead, it helps you do the much harder job of discovering, clarifying, and communicating what is important to you in the face of serious illness.

There Are 10 "Tools" in This Tool Kit:

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	THE PROXY QUIZ 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: ADVANCE PLANNING FOR HEALTH CARE

Tool #1

How to Select Your Health Care Agent or Proxy

Name & Date_____

When you decide to pick someone to speak for you in a medical crisis, in case you are not able to speak for yourself, there are several things to think about. This tool will help you decide who the best person is. Usually it is best to name *one* person or agent to serve at a time, with at least one successor, or back-up person, in case the first person is not available when needed.

Compare up to 3 people with this tool. The persons best suited to be your Health Care Agents or Proxies 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 next 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. Is someone you trust with your life.
				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.

The person you choose to make health care decisions for you is known by different names in different states. This person is sometimes called a health care agent, proxy, representative, attorney-in-fact, surrogate, or even patient advocate.

Who *Can't* Be a Proxy?

State rules for who may be a health care proxy vary, but the most common groups disqualified are these:

- Anyone under age 18.
- 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 PICK 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 with your proxy.
- Make sure your proxy gets a copy of your advance directive and a copy of the worksheets you used in this kit, and knows where to find the originals.
- Give your proxy a copy of *Tool # 9: Guide for Health Care Proxies*.
- Tell family members and close friends whom you picked.

HOW MUCH AUTHORITY SHOULD YOU GIVE YOUR AGENT?

Most people wish to give their agent the broadest authority possible to make all health care decisions when they are no longer able, including those about the use of life-sustaining treatments such as artificial nutrition and hydration. If you do not wish to give such broad authority to the proxy you have selected, think about what limitations you would impose and describe them here as best you can:

Key Question: If you include written instructions in your advance medical directive and there is a conflict between your proxy's instruction and your advance directive, which takes priority?

My agent's direction My advance medical directive

Tool #2

Are Some Conditions Worse Than Death?

Name & Date_____

This worksheet helps you to think about situations in which you would ***not*** want medical treatments intended to keep you alive. These days, many treatments can keep people alive even if there is *no* chance that the treatment will reverse or improve their condition. Ask yourself what you would want in the situations described below if the treatment would not reverse or improve your condition.

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.	No longer can recognize or interact with family or friends.	1	2	3	4	5
	*Comment*_____					
b.	No longer can think or talk clearly.	1	2	3	4	5
	*Comment*_____					
c.	No longer can respond to commands or requests.	1	2	3	4	5
	*Comment*_____					
d.	No longer can walk but get around in a wheel chair.	1	2	3	4	5
	*Comment*_____					
e.	No longer can get outside and must spend all day at home.	1	2	3	4	5
	*Comment*_____					
f.	Are in severe untreatable pain most of the time.	1	2	3	4	5
	*Comment*_____					

What If You . . .

		Definitely Want Treatment ←			→	Definitely Do Not Want Treatment
g.	Are in severe discomfort most of the time (such as nausea, diarrhea).	1	2	3	4	5
	*Comment*_____					
h.	Are on a feeding tube to keep you alive.	1	2	3	4	5
	*Comment*_____					
i.	Are on a kidney dialysis machine to keep you alive.	1	2	3	4	5
	*Comment*_____					
j.	Are on a breathing machine to keep you alive.	1	2	3	4	5
	*Comment*_____					
k.	Need someone to take care of you 24 hours a day.	1	2	3	4	5
	*Comment*_____					
l.	No longer can control your bladder.	1	2	3	4	5
	*Comment*_____					
m.	No longer can control your bowels.	1	2	3	4	5
	*Comment*_____					
n.	Live in a nursing home permanently.	1	2	3	4	5
	*Comment*_____					
o.	Other:	1	2	3	4	5
	*Explain*_____					

Tool #3

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 may choose a treatment and others reject it. A big question is, how much would you be willing to endure if the chances of regaining your current health were high? What if the chances were 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 treatments have **very severe side effects, such as severe pain, nausea, vomiting, or weakness that could last for months**.

Question: Would you be willing to endure such severe side effects 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**
Very, very low (less than 1 in 1,000)	**Yes**	**Not sure**	**No**

Additional comments:

Tool #4

Personal Priorities & Spiritual Values Important to Your Medical Decisions

Name & Date_____

People have personal priorities and spiritual beliefs that effect 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 clearer, 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, even if it makes you drowsy or puts you to sleep much of the time?

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?

13. Other priorities/values you want others to know.

Tool #5

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 donations—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 organs.
____ 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. But be sure to tell your proxy and loved ones. Make sure they will support your wishes. Even with an organ donor card, hospitals will usually 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. Would you like to do this?

Yes **Not sure** **No**

If you circle Yes, you must contact a medical institution to which you are interested in making this donation. Medical schools, research facilities, and other agencies need to study bodies to gain greater understanding of disease mechanisms in humans. But, this kind of donation must be accepted by the medical institution. Note that total body donation is ***not*** an option if you also choose to be an organ or tissue donor.

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. What are your thoughts about your memorial service—such as songs or readings you want, or the people you hope will participate?

8. Other preferences:

Tool #6

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 is this important?

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. (See *Tool #10 – Resources: Advance Planning*.)

- 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.

Tool #7

The Proxy Quiz 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 score 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 …

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

2. Which of the following do you fear *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…
   - You are now seriously ill, and doctors are recommending chemotherapy, and
   - This chemotherapy usually has very severe side effects, such as pain, nausea, vomiting, and weakness that could last for 2-3 months.

   Would you be willing to endure the side effects if the chance of regaining your current health was <u>less than 1 percent</u>?
   a. Yes
   b. No
   c. I am uncertain

4. In the same scenario, suppose that your condition is clearly terminal, but the chemotherapy might give you 6 additional months of life. Would you want the chemotherapy even though it has severe side effects (frequent pain, nausea, vomiting, and weakness)?
   a. Yes
   b. No
   c. 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?
   a. Yes
   b. No
   c. I am uncertain

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 until death comes?
   a. Antibiotic treatment
   b. Comfort care only
   c. I am uncertain

9. Imagine that…
   - You are in a permanent coma, and
   - You are dependent on a tube inserted into your stomach for nutrition and hydration, for 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 –

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 usually has very severe side effects, such as pain, nausea, vomiting, and weakness that could last for 2-3 months.

   Would ***N*** be willing to endure the side effects if the chance of regaining his/her current health was <u>less than 1 percent</u>?
   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 6 additional months of life. Would ***N*** want the chemotherapy even though it has severe side effects (frequent pain, nausea, vomiting, and weakness)?
   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

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 I-V 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 only
   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, for 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

- END -

Tool #8

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."

FIVE TIMES TO RE-EXAMINE YOUR HEALTH CARE WISHES…

Re-examine your health care wishes whenever any of the "Five D's" occur:

1. Decade – when you start each new decade of your life.
2. Death – whenever you experience the death of a loved one.
3. Divorce – when you experience a divorce or other major family change.
4. Diagnosis – when you are diagnosed with a serious health condition.
5. Decline – when you experience a significant decline or deterioration of an existing health condition, especially when it diminishes your ability to live independently.

IF YOUR WISHES CHANGE…

Make a new advance directive if your old one no longer reflects your wishes. Ask about the proper way to cancel or amend your existing directive in your state. If you change your advance directive, it is important to notify everyone who has copies of your old medical directive forms.

WHAT TO DO WITH YOUR ADVANCE DIRECTIVE

1. Keep the original copy of your health care advance directive and these work sheets or other notes some place they can be easily found.

2. Give your chosen proxy a copy of the directive plus any worksheets or notes. Make sure your proxy knows where to find the original.

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…

After completing your Advance Directive, **you may have to take one more step if you want to avoid CPR (cardio-pulmonary resuscitation) or other life support when an ambulance (911) is called.**

Some people with serious and irreversible conditions do not want an emergency medical team to give them CPR if their heart stops. If this is your wish, ask how to get a DNR Order (Do-Not-Resuscitate Order) that will be respected outside of hospitals. These are also called *Out-of-Hospital DNR Orders*, *Comfort-Care-Only Orders*, or by other similar names. They usually require your physician's signature and your consent. You will get a special identifying bracelet or document that must be visible if you have a medical crisis. If the emergency medical team sees the proper bracelet or document upon arrival, you can expect to receive all necessary comfort care—but not life support

Tool #9

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 these tests have risks associated with them?
   - ? Is the information you need worth the risk 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 now 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 is 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?

EIGHT THINGS A PROXY CAN DO TO OBTAIN GOOD CARE FOR THE PATIENT.

1. **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.

2. **Make yourself and your role known to the medical staff.** Make sure the advance directive is in the medical chart and medical personnel know its contents. Keep a copy yourself, handy, to show to people involved in the individual's medical care. Keep in touch with these people.

3. **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. Read the medical record every day.

4. **Push to make someone responsible for overall care.** Usually there are many medical personnel involved in the patient's care, none of whom wants to take full responsibility for the entire patient. Insist that one person be given overall responsibility to manage the patient's care and provide the necessary continuity during the entire period of care.

5. **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.

6. **Anticipate transfers.** Make sure when the patient is moved from one section of the hospital to another, or to a different facility, that you know the treatments to be continued or begun after the transfer. Meet with the medical team or head nurse to ensure that they are aware of the ordered treatment.

7. **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. Insist that medical issues be explained to you in words you can understand. 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. Be a squeaky wheel, if need be.

8. **Retain the help of a private care manager** if you are unable to work with the medical team on your own. A care manager usually has an advance nursing or social work degree. She or he can help you understand the medical record, attend care conferences, and advise you if the care is deficient or inappropriate.

Tool #10

Resources:
Advance Planning for Health Care

Here are some in-depth resources about end-of-life issues and advance medical directive forms.

GUIDES AND HANDBOOKS

A Good Death: Challenges Choices and Care Options, by Charles Meyer (1998). Down-to-earth, lay-language explanation of the implications of end-of-life care decisions from a religious and spiritual perspective. A 64-page paperback available in many bookstores.

Caring Conversations Workbook, published by the Center for Practical Bioethics (formerly the Midwest Bioethics Center), Town Pavilion, 1100 Walnut St., Ste. 2900, Kansas City, MO 64106-2197 (Tel. 816-221-1100). This is both a workbook and advance directive. It can be downloaded for free from their Web site: http://www.practicalbioethics.org. A comprehensive do-it-yourself workbook on planning for end-of-life care. (Parts of this tool kit were adapted from this publication.)

Handbook for Mortals: Guidance for People Facing Serious Illness, by Joanne Lynn, M.D., and Joan Harrold, M.D. (NY: Oxford University Press, 1999), available through the Web site of Americans for Better Care of the Dying www.abcd-caring.org. A most comprehensive and readable 242-page guide to dealing with serious, eventually fatal illness.

Hard Choices for Loving People: CPR, Artificial Feeding, Comfort Care and the Patient with a Life-Threatening Illness, by Hank Dunn. A&A Publishers, Inc., P.O. Box 1098, Herndon, VA 20172-1098 (Tel. 703-707-0174). Web site: www.hardchoices.com. A concise and helpful 48-page booklet on end-of-life decisions concerning resuscitation, food and fluids, hospitalization, and cure versus comfort care.

Making Health Care Decisions for Others: A Guide to Being a Health Care Proxy or Surrogate, by the Division of Bioethics, Dept. of Epidemiology and Social Medicine, Montefiore Medical Center, Albert Einstein College of Medicine, Bronx, NY. Available on their Web site: http://eph.aecom.yu.edu/WebApplication/UpLoad/AddInformation/Document/PROXY%20GUIDE.FINAL.doc. A guide every proxy or agent needs to read. (Parts of this tool kit were adapted from this publication.)

Your Life Your Choices–Planning for Future Medical Decisions: How to Prepare a Personalized Living Will, by Robert Pearlman, *et al.*, and the Veterans Administration Medical Center, Seattle, WA. A comprehensive do-it-yourself workbook on planning for end-of-life care. (Parts of this tool kit were adapted from this publication.) Available on the Web at http://www.hsrd.research.va.gov/publications/internal/ylyc.htm.

ORGANIZATIONS

Americans for Better Care of the Dying (ABCD), 3720 Upton St., N.W., Rm. B147, Washington, DC 20016 (Tel. 202-895-2660), is a non-profit public charity dedicated to social, professional, and policy reform aimed to improve the care system for patients with serious illness, and their families. Web page: www.abcd-caring.org .

Center for Practical Bioethics (formerly the Midwest Bioethics Center),Town Pavilion, 1100 Walnut St., Ste. 2900, Kansas City, MO 64106-2197 (Tel. 816-221-1100). A non-profit ethics resource center dedicated to a health care delivery system anchored in respect for patients and their families and guided by ethical discourse. They publish the *Caring Conversations Workbook*, described above. Web page: http://www.practicalbioethics.org

National Hospice and Palliative Care Organization (NHPCO), established in 1978, is a nonprofit organization whose mission is advocacy for the rights of terminally ill Americans. NHPCO is the largest nonprofit membership organization devoted exclusively to the promotion of hospice care in America. In addition to providing informational and educational materials to members, NHPCO provides information and referrals to the public. Web page: www.nhpco.org.

ADVANCE DIRECTIVE FORMS OF SPECIAL INTEREST

Caring Conversations Workbook, published by the Midwest Bioethics Center. This is both a workbook and advance directive. See Guides and Handbooks above.

Five Wishes Advance Directive. Published by Aging with Dignity. This nationally used and very popular advance directive focuses on ways of talking about health care wishes and needs. Can be purchased and downloaded from their Web site: http://www.agingwithdignity.org/5wishes.html. Also available by mail order from P.O. Box 1661, Tallahassee, FL 32302-1661 (Tel. 850-681-2010).

Shape Your Health Care Future with Health Care Advance Directives. Published jointly by the American Bar Association, the American Medical Association, and AARP. Available for free on the ABA Commission Web site at: www.abanet.org/aging.

The Medical Directive, by Linda L. Emanuel, M.D., and Ezekiel J. Emanuel, M.D. This more medically-oriented advance directive includes six illness scenarios. For each, you consider possible medical interventions and goals of medical care. It also includes a proxy designation form. Can be purchased and downloaded from their Web site: http://medicaldirective.org.