

Information contained in this booklet has been taken from materials provided or adapted by the American Bar Association's Commission on Legal Problems of the Elderly.

The ABA Commission is dedicated to examining the law-related concerns of older persons. Established by the American Bar Association in 1978, the Commission has sought to improve legal services for older persons, particularly through involvements of the private bar, and has explored legal issues, surrounding long-term care, health care decision-making, individual rights, guardianship, housing, social security, elder abuse, and public benefit programs. The multidisciplinary commission includes lawyers, judges, physicians, professors, aging network leaders, and advocates for older persons.



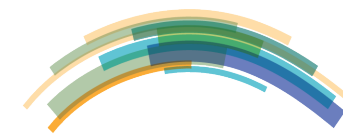
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DO YOU KNOW MY WISHES?



JOHNSON MCGINNIS
ELDER CARE LAW & ESTATE PLANNING

HELPING YOU PROTECT WHAT MATTERS MOST IN YOUR LIFE

This booklet was prepared by Johnson McGinnis Elder Care Law & Estate Planning, a Life Care Planning Law Firm that helps families throughout Middle Tennessee respond with confidence to the legal, financial, and personal challenges created by long life, illness and disability. Attorneys Barbara Boone McGinnis, CELA and Chris Johnson lead an interdisciplinary team of professionals who work together to maximize quality of life for elders and create welcome peace of mind for families.



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Introduction

What is a health care advance directive? It is a legal document (such as a *Living Will* or *Durable Power of Attorney for Health Care*) in which you authorize someone to make health care decisions for you if you are unable to do so yourself.

Just having a legal document may not be enough, however. How does the person you authorize to act for you – often called your *health care-proxy* or *agent* – know what to do for you in a time of crisis?

We have created this booklet to arm you and your health care agent with the tools you need to help make sure that decisions about your life and health are carried out in the way you would want them to, in case you are unable to make them yourself.

This booklet will help you reflect on your wishes and values. It will help facilitate open, honest conversation between you and your health care agent – about your values and your priorities, the meaning of your life and the quality of your life.

Planning involves ongoing conversation and discussions with your health care agent and members of your family. To help you in the planning process, this booklet offers you a variety of self-help worksheets, suggestions, and resources.

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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.
- 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, WA.

How to Select Your Health Care Agent or Proxy

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

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. 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.

Agents or Proxies rate well on these qualifications...

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.
- Make sure your proxy gets an original copy of your advance directive.
- Tell family members and close friends who you picked.

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, WA.

Are Some Conditions Worse than Death?

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...

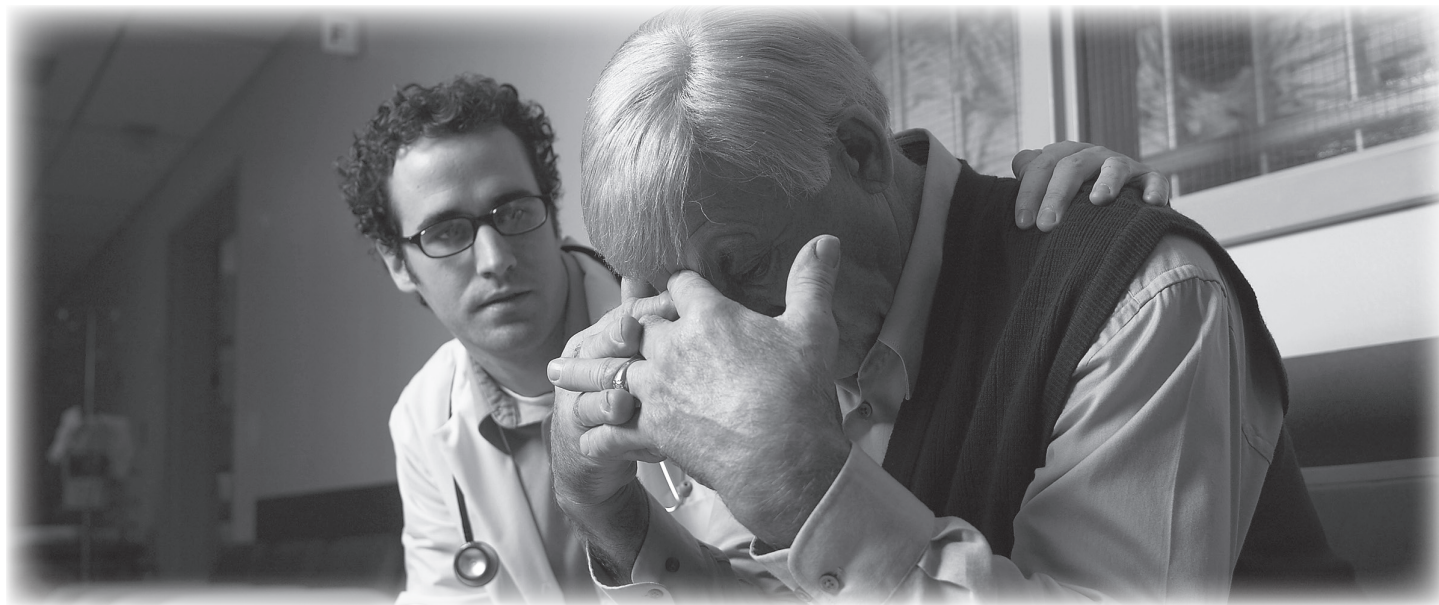
Definitely Want Treatment ← → Definitely Do Not Want Treatment

- | | | 1 | 2 | 3 | 4 | 5 |
|--|--|---|---|---|---|---|
| a. No longer can walk but get around in a wheel chair. | | | | | | |
| Comment _____ | | | | | | |
| b. No longer can get outside. You spend all day at home. | | | | | | |
| Comment _____ | | | | | | |
| c. No longer can contribute to your family's well being. | | | | | | |
| Comment _____ | | | | | | |
| d. Are in severe pain most of the time. | | | | | | |
| Comment _____ | | | | | | |
| e. Are in severe discomfort most of the time (such as nausea, diarrhea). | | | | | | |
| Comment _____ | | | | | | |

What If You...

Definitely Want Treatment ← → Definitely Do Not Want Treatment

- | | | | | | | |
|--|--|---|---|---|---|---|
| f. Are on a feeding tube to keep you alive. | | 1 | 2 | 3 | 4 | 5 |
| Comment _____ | | | | | | |
| g. Are on a kidney dialysis machine to keep you alive. | | | | | | |
| Comment _____ | | | | | | |
| h. Are on a breathing machine to keep you alive. | | | | | | |
| Comment _____ | | | | | | |
| i. Need someone to take care of you 24 hours a day. | | | | | | |
| Comment _____ | | | | | | |
| j. Can no longer control your bladder. | | | | | | |
| Comment _____ | | | | | | |
| k. Can no longer control your bowels. | | | | | | |
| Comment _____ | | | | | | |
| l. Live in a nursing home. | | | | | | |
| Comment _____ | | | | | | |
| m. Can no longer think or talk clearly. | | | | | | |
| Comment _____ | | | | | | |
| n. Can no longer recognize family or friends. | | | | | | |
| Comment _____ | | | | | | |
| o. Other: | | | | | | |
| Explain _____ | | | | | | |



How Do You Weigh Odds of Survival?

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 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 my 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

Personal Priorities & Spiritual Values Important to Your Medical Decisions

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, 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?

After Death Decisions to Think About Now

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** _____ If Yes, check one:
- Not sure** _____ I will donate any organs.
- No** _____ Just the following: _____

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

- Yes** _____ If Yes, check one:
- Not sure** _____ I will donate any organs. _____
- No** _____ Just the following: _____

Attention! If you circled **Yes** for question 1 or 2, 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 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 circled 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: _____



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...

- Before each annual physical exam.
- At the start of each decade of your life.
- 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.
- After any major medical change – such as being diagnosed with a serious disease or terminal illness. Or if such conditions worsen.
- After losing 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. Put your name and date on these worksheets.
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 (cardiopulmonary 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.

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?



