



Tool Kit

for Health Care

Advance Planning

AMERICAN **BAR** ASSOCIATION

Commission on
Law and Aging

ABA

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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.

There Are 8 “Tools” in This Tool Kit:

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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 8 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.

**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...***

<i>Name #1:</i>			
		<i>Name #2:</i>	
		<i>Name #3:</i>	
			1. Meets the legal criteria in your state to act agent or proxy. (This is a must! See next page.)
			2. Will listen to and respect your values, goals, and wishes.
			3. Will be willing to speak and act on your wishes and separate his/her own views from yours.
			4. Lives close by or could travel to be at your side if needed.
			5. Is someone you trust with your life.
			6. Will likely be available long into the future.
			7. Able to ask good questions and be a strong advocate in the face of an unresponsive doctor or institution.
			8. Will be able to handle conflicting opinions between family members, friends, and medical personnel.

Terminology: 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 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 values, goals, and wishes 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 our booklet, *Making Health Care Decisions for Someone Else: A How To Guide*.
- Tell family members, close friends, AND you health care providers whom you picked.

HOW MUCH AUTHORITY SHOULD YOU GIVE YOUR AGENT?

Most people wish to give their agent broad authority 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 authority to your proxy, what limitation would you impose and why? Describe it here as best you can:

KEY QUESTION: If you include written instructions in your advance medical directive and your proxy feels you would not want that instruction to apply to a particular medical situation that arises in the future, which takes priority? Keep in mind that medical decisions are often quite complex and unforeseeable, so your instructions today may not fit the medical circumstances of tomorrow.

(Circle one)

My Agent's Direction

My Advance Directive Instruction



Goals Near the End of Life

Name & Date _____

This worksheet helps you to think about situations in which your goals of care would change. These days, many treatments can keep you alive even if there is little or no chance that the treatment will reverse or improve your condition.

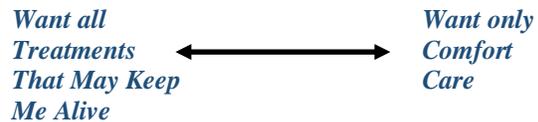
As one's condition declines, some people prefer that priority be given to pain and symptom management and comfort care, also called palliative care. Ask yourself what you would want in the situations described below if the treatment would not reverse or improve your condition.

Directions: Answer on a scale from 1 to 5 to indicate where your primary goal of care best fits on the continuum of care and treatment.

- ▶ **1** is a strong desire to have all treatments that may keep you alive no matter what.
- ▶ **5** is a strong desire only to be kept comfortable with pain and symptom management.

If you wish, you can add additional thoughts on the *Comment* lines.

What If You . . .



- | | | | | | |
|--|----------|----------|----------|----------|----------|
| | 1 | 2 | 3 | 4 | 5 |
|--|----------|----------|----------|----------|----------|
- 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. Are in severe untreatable pain most of the time.

1	2	3	4	5
----------	----------	----------	----------	----------

Comment _____
 - e. Are in severe discomfort most of the time (such as nausea, diarrhea).

1	2	3	4	5
----------	----------	----------	----------	----------

Comment _____
 - f. Are permanently dependent on machines For breathing, nutrition, and hydration.

1	2	3	4	5
----------	----------	----------	----------	----------

Comment _____

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:** 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:

Personal Priorities & Spiritual Values In Making 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.

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 112,000 patients are on the national organ transplant waiting list as of March 2020. Each day, 20 of them will die because the organs they need have not been donated. Every 10 minutes, a new name will be added to that waiting list.
- **Organs** you can donate: Heart, Kidneys, Pancreas, Lungs, Liver, Intestines, even hands and face.
- **Tissue** you can donate: Cornea, Skin, Bone Marrow, Heart Valves, the middle ear, veins, cartilage, tendons, and ligaments.
- 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.
- Even older and seriously ill patients who die have organs or tissue suitable for transplant. Doctors evaluate the options at or near the time of 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 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.

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. **Where 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:**



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 and avoid disagreements.
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 can be emotionally and financially costly.
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 dark. 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 tools provided in this packet as discussion starters or use any of the other workbooks and tools listed in the Health Decisions Resources List.
- 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.

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:

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

Words of Wisdom: The grade really makes no difference. It's the discussion the quiz engenders that counts.

The Quizzes are on the following pages ...

The Proxy Quiz

Step 1: Your 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 less than 1 percent?

 - 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 I-V 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 -

The Proxy Quiz

Step 2: Understanding the Personal Medical Preferences of (name)

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 the person named above (or "N") 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 less than 1 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 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 -



What to Do After Signing Your Health Care Advance Directive

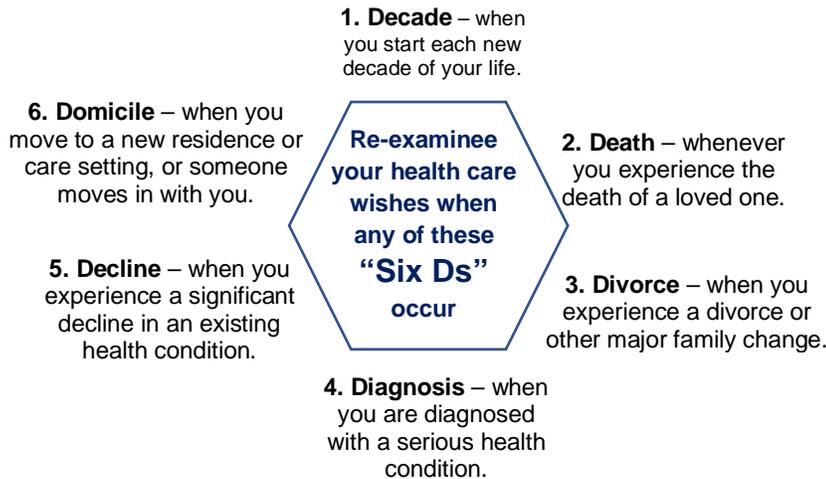
GOOD ADVANCE PLANNING IS A CONTINUING CONVERSATION

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."

MAKE SURE YOUR HEALTH CARE PROXY KNOWS THEIR JOB DESCRIPTION

Give your proxy a copy of the guide [*Making Medical Decisions for Someone Else*](#), which is downloadable with this Tool Kit. The guide describes in simple terms what it's like to be a health care proxy, what to do to get ready for the role, how to make the hard decisions, and where to get help.

SIX TIMES TO RE-EXAMINE YOUR HEALTH CARE WISHES...



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. Scan a copy so that you have it in digital form. Then use a smartphone app such as the ABA's [*Mind Your Loved One App*](#) ("MYLO") or MyDirectives.com to make your directive accessible by whomever you choose. See the Resource List for more information.
3. Give your chosen proxy a copy (paper or digital) of the directive plus any worksheets or notes. Make sure your proxy knows where to find the original or access it by their smartphone.
4. 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.
5. Carry an advance directive wallet card with you.
6. If entering a hospital or nursing home, provide them a copy via your smartphone or take a copy of your directive with you to give them. Ask that it be placed in your medical record.
7. Advance Directive Registries are available to store advance directives on the web securely. They enable health care institutions to access them electronically. You may wish to consider such a service.

IF YOU HAVE A SERIOUS, LIFE-THREATENING ILLNESS, ONE MORE STEP...

If you have a serious, life-threatening illness or advanced frailty, planning for how to respond to medical emergencies becomes very important. It requires something with more teeth than an advance directive – namely, a document that translates your priorities and wishes into a set of medical orders that will be followed by first responders and other health care providers. These medical orders are commonly known as POLST, for Provider Orders for Life-Sustaining Treatment, but they have other names in different states such as POLST, MOLST, MOST, an COLST.

A POLST must be completed only by an authorized health care provider and address the use of CPR if your heart or breathing stops, the level of care desired from full treatment to comfort care only, preferences about hospitalization, and sometimes other critical care decisions such as the use of artificial nutrition.

If your health care provider doesn't suggest a discussion about POLST, ask your provider if it would be appropriate for you. POLST requires your provider's signature and your consent or the consent of your authorized representative if you lack the ability to make medical decisions.