

# Planning //y Way A Guide for Future Health Care Decisions



### **Planning My Way: For Care Near** the End of Life



he mission of the Cunniff-Dixon Foundation is to enrich the physician-patient relationship near the end of life; to educate individual physicians and inspire them to provide the kind of care near the end of life that we all wish for ourselves and our loved ones.

While much work remains to be done, the progress in the last 10 years in end-of-life care has been considerable. But the reality is that a big share of the responsibility for the end-of-life experience that we all say we want rests on our own shoulders. We will each have our own ending, and there is much that we can do to prepare for it. The time to draw up a will is not at the very end of the journey. Likewise, there are things we can learn, questions we can ask about death and dving, today

when we are healthy and have time to reflect.

None of us wants to face these issues. But I know from personal experience that it makes a difference...a big difference. There were many issues that my wife Carley did not have to tackle at the end — she had already taken the time to plan.

Planning My Way is the Cunniff-Dixon Foundation's effort to make it easier, to provide a track to run on, with worksheets, questions and answers. It is the product of several years of collaboration and work by leading medical professionals. It can be extremely useful.

We hope that Planning My Way will help people answer questions in advance of that time when they may not be as able to make important decisions as they are today. We hope that it will help individuals and families prepare in advance for "the kind of care near the end of life that we all wish for for ourselves and our families."

Andy Baxter THE Founder CUNNIFF**DIXON** 



Planning My Way (PMW) is a project of the Cunniff-Dixon Foundation in collaboration with Robert Pearlman, MD, MPH, of the University of Washington and Melissa Bottrell, MPH, PhD of Ethics Quality Consulting. The vision, research, and testing of PMW originated with Dr. Pearlman and colleagues several years ago involving Veterans and their family members; and received broad review from a diverse panel of end-of-life and ethics experts including clinicians, clergy and consumer advocates. Our partnership helped bring that work forward to a consumer-oriented print and digital workbook experience that helps individuals and families

think about, learn and communicate what matters to them as they contemplate both legal and supporting future health care directives. The mission of the Cunniff-Dixon Foundation is to enrich the Doctor-Patient relationship near the end of life by fostering human development in medicine and supporting and funding projects relating to Palliative Care. Learn more at: www.cunniffdixon.org.

Learn more and find the complete set of worksheets at: **www.planninghealthcaremyway.org** 

FOUNDATION

If you or your organization would like to receive free Planning My Way workbooks, please contact our Director for more information: Andy Peters 1 Apeters008@gmail.com

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## **Planning** *Jy Jy* A Guide for Future Health Care Decisions Near the End of Life

Inly one person is truly qualified to tell your health care providers how you feel about different issues—and that's YOU.

Some people believe that doctors know best and therefore should make all the decisions. However, as a patient, your values and goals are very important and should be the guiding force behind your care. Your health care providers have technical knowledge and years of experience, but without your help they can't know what's best for you given your specific medical situation.

Every patient is different. Two patients with the same condition can have very different ideas about what kind of treatment they want. Have you thought about what kinds of medical care you would choose if you couldn't tell your providers what you wanted?

Through advance care planning, you can help ensure that your wishes will guide future care.

Planning My Way... A Guide for Future Health Care Decisions is an educational resource designed to help you with advance care planning.



#### For most of us, it's hard to think about the end of life.

Care at this time can suddenly become complex and overwhelming, with no clear path as to what types of interventions (if any) are appropriate.

While forms like advance directives or living wills can address legal requirements to support your health care wishes, they may not give your family or your doctor peace of mind that they are abiding by your wishes when they have to make hard decisions.

The explanations, examples, and worksheets provided within the Planning My Way materials help you refine and personalize your own instructions. Depending on your personal health circumstances, different worksheets might be most helpful in communicating your wishes to your spokesperson, loved ones, and health care providers. In addition, writing a personal letter to your family or creating an audio or video recording helps them feel confident that they are doing the best they can to follow your wishes.

Advance care planning is not necessarily a one-time activity—it should be revisited when life circumstances have changed. Planning My Way materials similar to this booklet are available for people who are healthy and who are living with a significant or chronic medical condition.

If life-sustaining treatments were the only way to keep you alive, would you want your doctors to use them? For some people, the answer is "Of course." For other people, the answer is "Never." For others, the answer would depend on the situation.

The worksheets in this document will help you think about things, like:

- Would or wouldn't you want life-sustaining treatments and when?
- How do you want to spend your last days?

For more information, go to: www.planninghealthcaremyway.org

## What is advance care planning?

Advance care planning is a step-by-step process to help you plan for medical decisions in your future.

Advance care planning involves five main actions:

Thinking about what you would want if you had to make difficult choices.

Talking about your views with your spokesperson, loved ones, and health care providers.

**Choosing** a spokesperson who can speak for you if you can't speak for yourself. Some people might call this person your surrogate or proxy.

**Completing** an advance directive to document your preferences, including using worksheets.

**Creating** a personal letter or audio or video recording to share your wishes.



## Why plan ahead?



Different people want different things.

### Mr. Ruiz has chronic health issues

#### **CONSIDER HIS STORY:**

Carlos Ruiz has had severe heart disease for years. His doctor said, "Your heart is very weak, and it will keep getting weaker. Now we need to make some decisions about what you want for your care. One thing we could do is focus on supporting your heart, lungs, and other vital organs to extend your life for as long as possible. If you got sick, you would go to the hospital for treatment, possibly into the ICU (intensive care unit). If the treatment was successful, you would go home. But you would probably be weaker. The other thing we could do is make our top priority the relief of your shortness of breath and discomfort, even if it meant you might not live as long. Which of these options sounds right for you?"

Mr. Ruiz said, "I've lived with this bad heart for a long time, but I'm not quite ready to give up. I'd like to try simple treatments, especially if I can receive them at home. I'd rather not leave my family and friends. I would prefer being comfortable at home. If you think going to the hospital would make a really big difference, I might consider it. But if going to the hospital only buys me a few extra days or weeks, I'd rather stay home, even if it means I don't live as long." Mr. Ruiz's doctor referred him to a nursing agency, and a nurse started visiting him at home. He got a few lung infections that made it hard for him to breathe, but they were cured by antibiotic pills that he took at home. Then he got another infection that didn't get better, even though he was taking antibiotics. He had a high fever and was so sick that his wife had to decide what to do. His doctor and his nurse said that they could put him in the hospital to treat his infection. This would relieve his symptoms and might prolong his life, but he would be separated from many of his family members and friends. Or he could stay home and be treated for his pain and discomfort until he died from the infection.

Mrs. Ruiz sent him to the hospital because she thought he might get better and could return home for a little while longer.

> If you were in this situation, would you have wanted to go to the hospital or stay home? Why?

## Talking About Your Wishes.

ne of the most important steps in advance care planning is talking about your wishes with the people who might be asked to speak for you.

Even if you don't complete a formal advance directive, it's important that you speak about your wishes clearly with your spokesperson, loved ones, and health care providers.

Talking with other people can also help you think about what you want. Often, friends and family members can ask you questions or tell you things that will make you think about your wishes in a different way.

It will be easier for everyone to follow your choices if you are able to say what you want thoroughly and clearly.

> Talking with other people can also help you think about what you want.

## How to start the conversation

here is no "right way" or "right time" to start this conversation. The best thing to do is set a time and get started. But what if your spokesperson or loved ones don't want to talk? What if they make excuses like, "You've got a lot of life left in you. Why do we have to talk about this now?" Here are some suggestions for getting a conversation started:

#### RELATE A STORY YOU READ HERE.

If there was a story in this booklet that resonated with you, it may also get the attention of the people with whom you want speak. Share the story with them and the questions it raised. Let them know what you are concerned about and why this is important to you.

#### REMIND THEM OF A SITUATION SOMEONE ELSE EXPERIENCED.

Another way to introduce the topic is to think about friends or relatives who had an illness and faced a difficult situation.

"Do you remember what happened to [name of person] 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."

#### BE FIRM AND STRAIGHTFORWARD. If someone puts you off because they are uncomfortable, you could say:

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

### POINT OUT THE POSSIBLE CONSEQUENCES OF NOT TALKING NOW.

Someone may be more willing to talk if you start by saying something like:

"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."

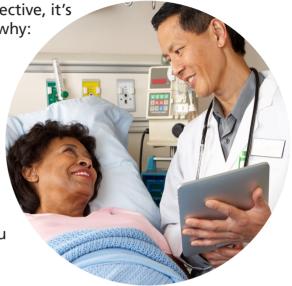
# Why you should talk to your health care providers

Whether or not you decide to complete an advance directive, it's still important to talk to your health care team. Here's why:

- Your doctor, nurse, social worker, chaplain, and other members of the health care team are there to help and support you and your loved ones as you discuss these important topics.
- Your health care providers can help you understand what steps you need to take to ensure that your wishes are honored.
- Your health care providers can answer questions you may have about your current health, treatments, or what might happen to you.
- You can't assume that your health care providers understand your values and preferences unless you talk to them.
- Your health care providers need to know your choice of a spokesperson if you become so sick that you aren't able to speak for yourself anymore.
- Your health care providers may be able to help prevent conflicts about your future care.
- You want to be sure that your health care providers will interpret your wishes or your advance directive in the way that you intend. There could be a problem if they believe your words mean one thing, while your spokesperson or family members believe your words mean something else.

You don't want to be in a hurry when you have this conversation. Make a special appointment with your health care providers to make sure that you have their attention and sufficient time for the discussion.

Doctors and nurses are people, too. Some are uncomfortable talking about advance directives or have other things on their minds. Research has shown that almost all patients want to discuss their future health care preferences, but many times their health care providers don't start the discussion. You can be gentle but assertive when you let your health care providers know that you really want to have this conversation.





# What to say to your health care providers

on't let your health care providers file your advance directive in your chart without discussing it with you. Make sure they know why you feel the way that you do. This will make it easier for them to understand and follow your wishes.

Bring a copy of your advance directive and any Planning My Way worksheets you chose to complete. You can also share your personal letter or audio or video recording, if you have created one. This will help you organize your thoughts and cover all the important topics.

During your appointment, you may want to ask some or all of these questions:

"Is it likely that I will lose my ability to make my own decisions because of my medical condition?"

"What difficult treatment decisions am I likely to face in the future because of my medical condition? What are the pros and cons of the different options?"

"Can I count on you to listen to my spokesperson if I can't speak for myself?"

"What will happen if you're not the health care provider who's there when I need care? How will my other health care providers know about my wishes?"

## Choosing Your Spokesperson

## Why appoint a spokesperson?

our first step in planning your future care is to appoint a spokesperson. (You may also hear this person called your surrogate or proxy decision maker.) You do not have to do so. It's entirely voluntary. But if someday you are unable to make your own health care decisions, your doctors and other providers will have to choose another person to make those decisions for you. If you do not appoint a spokesperson for yourself ahead of time, one will be appointed for you, usually your next of kin (spouse, parent, or sibling). If the spokesperson you would choose is different from the one that your health care organization would choose, it is very important that you formally appoint that person as your health care agent by completing an advance directive.

The rules for what that spokesperson is allowed to do may be different, depending on what state you live in. You should speak to a legal expert to find out the rules. f you have close family members, you may think that you don't need to choose a spokesperson. After all, if you do not appoint a spokesperson and can't speak for yourself, your doctors will ask your spouse to speak for you, or other relatives if you are not married.

However, it's not always that simple. If your family members disagree about your treatment, it can be very difficult to make decisions. And if you don't have a family or are not close to your family, your doctors might have to turn to someone who doesn't know what you would want.

These are just two reasons why you might want to choose a particular individual to be your spokesperson. You may have other reasons. For example:

- You might have several children but think that one would be a better spokesperson.
- You expect strong feelings among your family members and want to let everyone know ahead of time who should speak for you.
- You may be more comfortable telling a particular person how you feel about future health care choices you might have to make.

A Durable Power of Attorney for Health Care document tells your health care providers whom you want to make medical decisions for you if you get too sick to decide for yourself. It is included in most advance directive forms.



When choosing your spokesperson,

#### CONSIDER ALICE ROBERTS' STORY:

Alice Roberts assumed her doctors would let her closest friend, Larry Jergen, make decisions about her medical treatment if she was ever unable to make them herself. He'd been visiting her daily since she had entered the final stages of lung cancer.

They often talked about her wishes. But then Mrs. Roberts developed an infection with a high fever, and she became confused. Her doctors felt that they should talk to her next of kin before deciding whether to give her antibiotics. Her next of kin was her brother Frank, who lived in another state. Frank and Mr. Jergen disagreed about what medical treatment Mrs. Roberts should receive. Mrs. Roberts had never spoken about this with her brother. But because Mr. Jergen was not related to Mrs. Roberts and she had not legally selected him as her spokesperson, the doctors let Frank make the decisions.

## What to talk about ?

hen you ask someone to be your spokesperson, you're asking for a big responsibility. You and your spokesperson want to be comfortable with this. You don't want this person to agree to be your spokesperson if they really have strong doubts.

To start the conversation, you can ask questions like:

"I've been doing some thinking about who might be able to speak on my behalf regarding my medical care if I can't speak for myself. Would you consider doing it?"

'Would you feel comfortable doing this?'

"Do you think you can make decisions for me that are based on my values, preferences, and wishes, even if they're different from yours?"

If the person agrees to be your spokesperson, you can reassure them that you aren't expecting them to be "superhuman" or "all knowing." Tell them they have your permission to make decisions for you. This is especially important for situations that you haven't discussed or can't predict.

Encourage them to make decisions according to how they think you would.

# Once you've chosen your spokesperson

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nce your spokesperson has agreed, you should let your loved ones know that you have chosen a spokesperson and tell them whom you have chosen. This is especially important if your spokesperson isn't a member of your family. You might say something like this:

I've asked [name of the person you've chosen] to be my spokesperson in case I need medical care and can't speak for myself. After careful thought, I feel that [person's name] is the right person to handle this responsibility.

Also, you should let family and friends know if you filled out a Durable Power of Attorney for Health Care document to legally appoint your spokesperson as your health care agent. You should provide your loved ones with a copy of the document.

## Completing your **Advance Directive**

#### WHAT IS AN ADVANCE DIRECTIVE?

An advance directive is a legal document that helps your spokesperson, doctors, and loved ones understand your wishes about your future health care.

Advance directives can be proxy or instructional.

Proxy vs. Instructional Directives. Proxy directives are written instructions that tell your health care providers whom you want to make decisions for you if you get too sick to decide for yourself. Examples are a Durable Power of Attorney for Health Care or a Medical Power of Attorney.

Instructional directives are written instructions that tell your health care providers which treatments you want and don't want if you get too sick to decide for yourself. Common examples are a Living Will or a Directive to Physicians. A special type of instructional directive is a mental health (or psychiatric) advance directive—for patients with mental health problems that might interfere with their ability to make health care decisions.

Which advance directive is right for me? State law generally determines what is legally binding. Even when an advance directive is not legally binding, it still helps your health care providers, spokesperson, and loved ones understand your wishes.

Which parts of the advance directive form should I complete? You may choose to complete only the Durable Power of Attorney for Health Care section. You can also choose to complete only the Living Will section. Or you can complete both sections.

If you have someone you trust to make decisions on your behalf, we recommend that you complete the Durable Power of Attorney for Health Care. You might consider completing only this section if you want to give your spokesperson complete freedom to decide what is in your best interests given your specific medical situation. If you want to give specific instructions, you can complete the Living Will section. You can also provide additional information by attaching any of the Planning My Way worksheets.

If you have questions, discuss this with your health care provider. Remember to tell your loved ones what you've chosen and share with them your personal letter or audio or video recording.

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## How often should I review my advance directive?

#### Your circumstances affect when and how often you review your advance directive.

It's important to review your advance directive even if you're healthy. A regular review prepares you and your loved ones for emergency situations, such as a car accident or a sudden illness.

Consider reviewing your advance directive annually:

- Before a medical check-up
- Near a special event, such as a yearly family gathering or birthday

It's also important to review your advance directive when major changes happen.

Here are some things to think about if your health condition changes, especially if it takes a turn for the worse:

#### ADJUSTING TO NEW HEALTH PROBLEMS

If you develop a new problem that seriously affects your health or function, you might think differently about your values and preferences. If you develop a new health problem, first give yourself some time to get used to your new situation. Then, take another look at your advance directive and your worksheets to see if your thoughts have changed.

#### NEARING THE END OF LIFE

If you learn that you might die within a certain period of time, you might rethink your priorities. Your attention might shift to making the most of the time that you have left.

It's also important to think about your wishes when other circumstances change.

You may need to rethink who will speak for you if:

- A family member dies
- You get a divorce
- Your spokesperson moves





Worksheets help you as you work on your advance care plan. The following pages contain selected worksheets (highlighted in purple) to help you get started.

All of the Planning My Way worksheets, along with additional advance care planning information, are available on our website: **www.planninghealthcaremyway.org** 

Choosing a Spokesperson

- Imagining Different Situations
- My Strongly Held Beliefs
- Who to Contact in an Emergency
- Taking Care of What I Value
- Mental Health Care Preferences

When I Would or Wouldn't Want Life-Sustaining Treatments

- My Last Days
- Organ Donation and Autopsy
- Burial and Funeral Arrangements
- Advance Directive (varies by state)



Life-sustaining treatments are medical treatments that keep you alive for a while but don't cure you or make you better. They include

- CPR (cardiopulmonary resuscitation)
- Breathing machines (mechanical ventilators)
- Kidney dialysis
- Feeding tubes(tubes that provide water and liquid food)

Just like people have very different views about how they want to live, people also have different ideas about their death. Some people want treatments that will keep them alive as long as possible in all situations. Others feel strongly that they wouldn't want these treatments.

As you think about life-sustaining treatments, remember the experiences you've had with your own family or friends. Also remember that it's hard to know what your life would really be like with serious physical or mental problems, unless you've had direct experience. Healthy people may assume that a serious health problem or a severe disability would make their lives terrible. But people often change their minds when their health starts to get worse. This means that how you feel today might not be how you would feel later if your health got worse. In fact, many people learn to adjust to these situations very well.

## If you want to indicate your general views about life-sustaining treatments, check one of the boxes below: (Part 1 of 2)

□ I'd always want my doctor to use medical treatments to prolong my life as long as possible, no matter what my situation is. I can't imagine any situation in which I wouldn't want my doctor to use life-sustaining medical treatments.

□ I'm not sure. There might be some situations in which I wouldn't want my doctor to use medical treatments to prolong my life as long as possible.

There are definitely some situations in which I wouldn't want my doctor to use medical treatments to prolong my life as long as possible.

### When I Would or Wouldn't Want Life-Sustaining Treatments

Imagine that in the future you have a serious health condition that your doctors expect to be permanent. You're too sick to make your own healthcare decisions. Next, imagine that someone needs to decide whether to use life-sustaining treatments on you.

Think about each situation on the left side of the charts and ask yourself, "In this situation, would I want life-sustaining treatments?" In other words, would you want your doctor to use (or continue) life-sustaining treatments to prolong your life? Or, instead, would you want your doctor not to provide life-sustaining treatments (or to withdraw them) and allow you to die? Or, are you not sure because your answer would depend on the circumstances? Remember as you fill out this worksheet that you're too sick to make your own health care decisions.

#### Medical Situations: (Part 2 of 2)

Medical Situation	I would want life- sustaining treatments.	I'm not sure. It would depend on the circumstances.	I would NOT want life- sustaining treatments.
If I am unconscious, in a coma, or in a vegetative state and there is little or no chance of recovery.			
Explanation (i.e., comments, clarifications):			li
If I have permanent, severe brain damage that makes me unable to recognize my family or friends (for example, severe dementia).			
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Explanation (i.e., comments, clarifications):

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If I have a permanent condition where other people must help me with my daily needs (for example, eating, bathing, toileting). Explanation (i.e., comments, clarifications):		
		1.
If I need to use a breathing machine and be in bed for the rest of my life. Explanation (i.e., comments, clarifications):		
If I have pain or other severe symptoms that cause suffering and can't be relieved. Explanation (i.e., comments, clarifications):		
If I have a condition that will make me die very soon, even with life-sustaining treatments. Explanation (i.e., comments, clarifications):		

		h
Other:		
Explanation (i.e., comments, clarifications):		
		h
Other:	0	
Explanation (i.e., comments, clarifications):		
		ĥ



## Planning My Way

Many people feel strongly about what would be important to them at the very end of their lives. Some people want to have certain things happen. Others want to make sure to avoid things that they fear or don't like.

What are some of the things that are most important to you? Use this worksheet to discuss your choices with your spokesperson, loved ones, and health care providers.

You may attach a copy of this optional worksheet to your Advance Directive if you choose to complete one. Be sure to initial each page. If you give the worksheet to your health care provider, it will become part of your medical record, and will be protected like your other medical information. If you do this your health care provider will treat the worksheet as part of your directive.

Medical Situation	Not important	Moderately Important	Very Important	Extremely Important
Avoiding pain and suffering.				
Being alert.				
Being around my family and close friends.				
Being able to feel someone next to me or touching me.				
Being able to tell my life story and leave good memories for others.				
Having religious or spiritual advisors at my side when I die.				
Reconciling differences and saying "good-bye" to my family and friends.				
Being at home when I die.				
Being in a hospital when I die.				
Staying alive long enough for my family to get to my bedside before I die, even if I'm unconscious.				
More information:				



Sometimes the organs and tissues of someone who has died can help other people who need them. You might want to donate your organs after you die. Or you might not want to. You can use this worksheet to help communicate your preferences for organ donation to others.

You can also use this worksheet to indicate whether you want to allow all or part of your body to be used for medical research

You can also indicate whether you want to have an autopsy after your death. The value of an autopsy is to understand disease and to train future health care professionals. After an autopsy, your body can be shown and buried. Your family members may be asked to give their consent for an autopsy. You can help them by indicating your preferences on this worksheet. Note that outside the health care system, there may be a charge for an autopsy in certain cases.

## Do you want to donate your usable organs and tissues to other patients? (Check one)

			If you choose "yes" you should:
□ Yes	□ No	Not Sure	<ul> <li>Fill out an organ donor card</li> </ul>
			<ul> <li>Tell your loved ones</li> </ul>

## Do you want all or part of your body to be used for medical research? (Check one)

🗆 Yes
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🗌 No

Not Sure

#### Would you allow an autopsy? (Check one)

🗆 Yes

☐ Yes, but with the following limitations:

🗆 No

Not Sure

### **Burial and Funeral Arrangements**

## Planning My Way

People often leave instructions for what they want their loved ones to do with their bodies after they die. Some want to be buried in a particular place, maybe in a cemetery with other family. Other people would prefer to be cremated. They might want to have their ashes put in a special place.

People also have different ideas about their funerals and memorial services. These services are often very comforting for family and friends because they celebrate and honor the life of a loved one. Services also can make a statement about your religious faith.

You can use this worksheet to help communicate your preferences to your loved ones. After completing the worksheet, initial each page, and keep a copy of it with your other important papers, such as your will. Give a copy of the completed worksheet to your loved ones.

#### I would prefer to be: (Select one.)

Buried
Cremated
No preference

I would like my remains to be put: (Enter your answer below.)

#### Other preferences:

Write down any thoughts you have about your funeral or memorial service on additional pages, such as:

- Where it should be held
- Songs or readings to include
- Where donations should be sent



Many people have special personal or spiritual beliefs that they want to have respected in decisions about life-sustaining treatments. Do you? Use this worksheet to discuss your choices with your spokesperson, loved ones, and health care providers.

You may attach a copy of this optional worksheet to your Advance Directive if you choose to complete one. Be sure to initial each page. If you do this your health care provider will treat the worksheet as part of your directive. If you give the worksheet to your health care provider, it will become part of your medical record, and will be protected like your other medical information.

I have religious beliefs that influence my views about the use of medical treatments. For example, some people believe that it is wrong to receive blood products, such as plasma or red blood cells. My beliefs are:

I believe in other forms of treatment, such as acupuncture, herbal remedies, or other alternative practices. I want the following treatments to be considered as part of my care:

I gain strength from other things like family, prayer, being in nature, reading, inspirational literature, or music. I want the following things included as part of my care:

#### My Strongly Held Beliefs- Continued

My Beliefs	Yes	Νο	Not sure	Explanations of my beliefs
I should always be given food and fluids to prolong my life, even if it means I would need surgery to place a tube in my stomach.				
I want to have my pain controlled, even if a side effect of the pain medication is that I can't think clearly.				
My spokesperson should consider my religious and spiritual views when making health care decisions on my behalf.				
In addition to my interests, my spokesperson should consider his or her own interests and the interests of my family when making health care decisions on my behalf.				
My spokesperson should consider my views about the financial impact of treatment on my loved ones when making health care decisions on my behalf.				
My spokesperson should follow my advance directive as closely as possible, even if he or she doesn't think that it's in my best interests.				
Other				1.
Other				

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For more information visit planninghealthcaremyway.com



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