

Planning *My Way*

A Guide for Future Health Care Decisions



Planning My Way:
While Healthy



The 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 dying, 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
Founder

THE
CUNNIFF  DIXON
FOUNDATION

Planning *My Way*

A Guide for Future Health Care Decisions While Healthy

Only 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.





The best time to consider advance directives

is when you are in good health. This gives you the opportunity to fully express your wishes in a clear state of mind.

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 living with a significant or chronic medical condition and who require care near the end of life.

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.

Consider Grace Chen's story



Grace Chen was 35 years old when she was hit by a car while riding her bicycle. She was taken to the hospital, where she went into a coma. She lay in bed with her eyes closed. She didn't respond when people spoke to her and she didn't wake up. She also couldn't breathe or eat on her own. Grace was put on a ventilator, or breathing machine, that pumped air into her lungs. She also had a feeding tube in her throat so that liquid food and fluids could go straight into her stomach.

Grace was single, so her doctors asked her parents to decide about her treatments. The doctors thought it was possible that Grace could come out of the coma. But they said that it could take anywhere from one week to one year. They said that the longer Grace stayed in a coma, the less likely it was that she would ever wake up. And if she did come out of the coma, they said, she would probably have some brain damage. The damage could be mild or it could be severe. Grace might need help taking care of herself and might not be able to live alone.

Grace had never said what she would want if she were in an accident. After two months, Grace was still unconscious. A brain scan showed severe injury to many parts of her brain. The doctors thought this gave Grace a very low chance of ever waking up.



If you were in Grace's situation, what would you want your parents to do? Why?

Are your views similar to those of Ms. Santini?



Ms. Santini:
If I'm ever in this situation, I'd want to be kept on the ventilator and the feeding tube for as long as possible. As long as I was not in terrible pain all the time, I would want to extend my days for as long as possible and allow every chance that I could wake up. I want to live my life as long as I possibly can.



Mr. Johnson:
I can't stand the thought of being unable to recognize or communicate with my family! I would not want to be connected to all those machines and tubes. I would tell my family, "Please don't keep me on those machines. Just make me comfortable."

Are your views similar to those of Mr. Johnson?





Advance care planning may help prevent conflicts in your family.

CONSIDER SGT LARSEN'S STORY:

SGT Larsen is a 22-year-old patient. While serving in combat he was severely injured in an explosion. The explosion caused brain damage and left him unable to communicate. Doctors didn't know how much his brain would recover. The explosion also damaged his spinal cord, leaving him paralyzed from the waist down. The paralysis would be permanent

Since SGT Larsen couldn't communicate his own medical decisions, the doctors asked his family. His parents told the doctors to "do everything possible" to keep him alive, regardless of his chances for recovery. They believed their son shared their views on the value of life.

However, SGT Larsen's sister was against using technology that might add to her brother's suffering, even if it kept him alive. She believed that he wouldn't want to live after being injured so severely. She had spoken with him before he went into combat. He told her his greatest fear was getting injured so severely that he would be unable to do the things he loved most.

The doctors followed the directions from his parents because his parents were the legal next of kin. After several months, SGT Larsen's condition stabilized enough that his parents could care for him at home. Sadly, the disagreement in the family caused hard feelings that lasted for many years.

Talking About Your Wishes.

One 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

There 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.

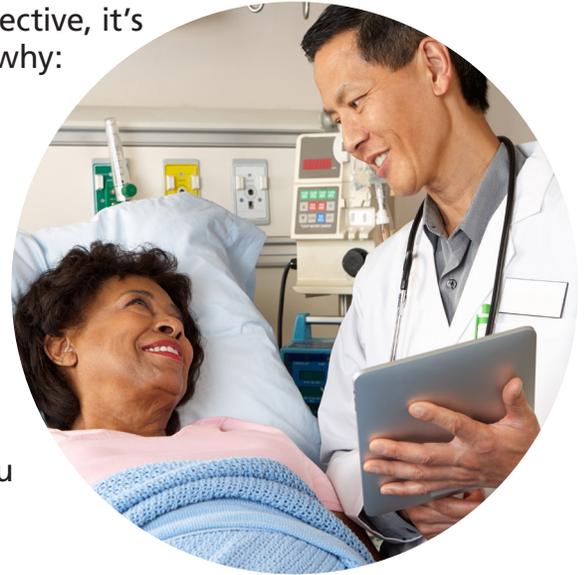
Someone may be more willing to talk if you start by saying something like:

“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

Don'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?

Your 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.

If 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 ?

When 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



Once 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.

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



Planning *My Way*

WORKSHEETS

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

As you fill in this worksheet, remember that in each situation you've lost the ability to make your own health care decisions.

If I am unconscious, in a coma, or in a vegetative state and there is little or no chance of recovery...

What would you most want to happen if you were in this situation? What would be meaningful or important to you?

What would you most want to avoid if you were in this situation? What would you be most concerned about?

If I have permanent, severe brain damage that makes me unable to recognize my family or friends (for example, severe dementia)...

What would you most want to happen if you were in this situation? What would be meaningful or important to you?

What would you most want to avoid if you were in this situation? What would you be most concerned about?

If I have a permanent condition where other people must help me with my daily needs (for example, eating, bathing, toileting)...

What would you most want to happen if you were in this situation? What would be meaningful or important to you?

What would you most want to avoid if you were in this situation? What would you be most concerned about?

If I need to use a breathing machine and be in bed for the rest of my life...

What would you most want to happen if you were in this situation? What would be meaningful or important to you?

What would you most want to avoid if you were in this situation? What would you be most concerned about?

If I have pain or other severe symptoms that cause suffering and can't be relieved...

What would you most want to happen if you were in this situation? What would be meaningful or important to you?

What would you most want to avoid if you were in this situation? What would you be most concerned about?

If I have a condition that will make me die very soon, even with life-sustaining treatments...

What would you most want to happen if you were in this situation? What would be meaningful or important to you?

What would you most want to avoid if you were in this situation? What would you be most concerned about?

In addition to appointing a spokesperson, you may want to communicate information about your emergency contacts. Are there certain people you want your health care providers to contact if you have a medical emergency or mental health crisis? Are there people you don't want your health care providers to contact?

After completing the optional worksheet, initial each page and keep a copy of it with your other important papers. Give a copy to your health care provider to put in your medical record. 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.

Emergency Contacts

I would like to have the following person (people) contacted in case of a medical emergency (e.g., hospitalization) or mental health crisis.

Name:	Home Phone:
Street Address:	Office Phone:
City/State/Zip:	Email:

Name:	Home Phone:
Street Address:	Office Phone:
City/State/Zip:	Email:

Name:	Home Phone:
Street Address:	Office Phone:
City/State/Zip:	Email:

Spiritual Advisor

I would like to have my pastor, priest, rabbi, or other spiritual advisor consulted regarding any difficult health care decision that must be made on my behalf. (If no, leave blank.)

Name:	Home Phone:
Street Address:	Office Phone:
City/State/Zip:	Email:

Do Not Notify

I do NOT want the following people notified in case of a medical emergency (e.g., hospitalization) or mental health crisis.

Name:	Home Phone:
Street Address:	Office Phone:
City/State/Zip:	Email:

Name:	Home Phone:
Street Address:	Office Phone:
City/State/Zip:	Email:



Who to Contact in an Emergency (continued)

Do Not Visit

I do NOT want the following people to visit me in case of a medical emergency (e.g., hospitalization) or mental health crisis.

Name:	Home Phone:
Street Address:	Office Phone:
City/State/Zip:	Email:

Name:	Home Phone:
Street Address:	Office Phone:
City/State/Zip:	Email:

Name:	Home Phone:
Street Address:	Office Phone:
City/State/Zip:	Email:

Name:	Home Phone:
Street Address:	Office Phone:
City/State/Zip:	Email:

Name:	Home Phone:
Street Address:	Office Phone:
City/State/Zip:	Email:

Name:	Home Phone:
Street Address:	Office Phone:
City/State/Zip:	Email:

About Planning my Way

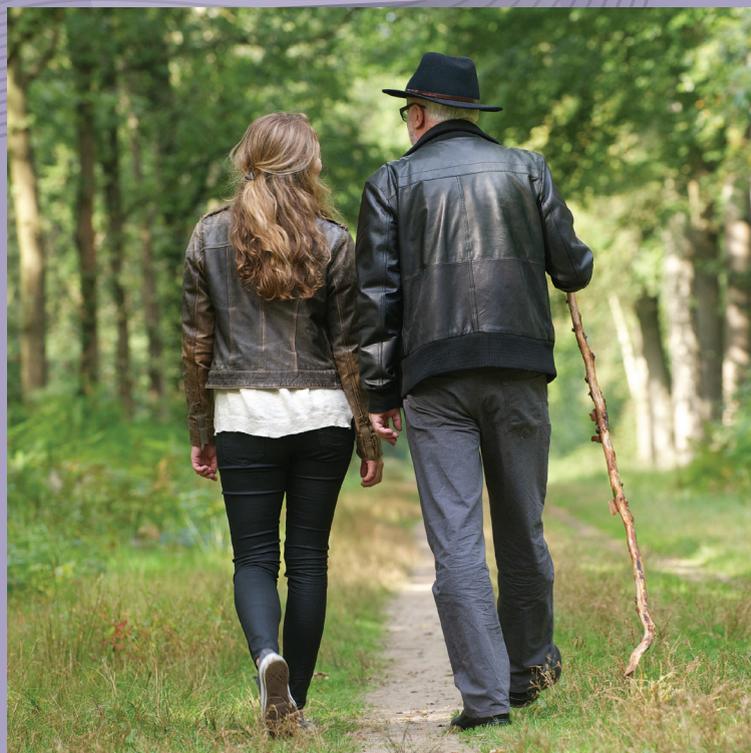
Planning My Way (PMW) is a project of the Cunniff-Dixon Foundation in collaboration with Robert Pearlman, MD, MPH, of the University of Washington and Melissa Bottrell, MPH, PhD of Ethics Quality Consulting. The vision, research, and testing of PMW originated with Dr. Pearlman and colleagues several 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

If you or your organization would like to receive free Planning My Way workbooks, please contact our Director for more information:
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