

Planning for Future Health Care Decisions... *My Way*

A Workbook for Advance Care Planning

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Planning for Future Health Care Decisions... My Way



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 should make all the decisions. However, VA believes that patients' values and goals are very important and should guide decisions about treatment. Your health care providers have technical knowledge and years of experience. But without your help, they can't know what's best for you.

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 assure that your wishes will guide your future health care.

Planning for Future Health Care Decisions



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PLANNING...MY WAY

What is advance care planning?

Advance care planning is a step-by-step process to help you plan for medical decisions in your future. *Planning for Future Health Care Decisions...My Way* is an educational resource designed to help you with advance care planning.

Advance care planning involves four main actions:

- **Choosing** a spokesperson. Your spokesperson can speak for you if you can't speak for yourself; some people might call this person your surrogate.
- **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.
- **Completing** an advance directive to document your preferences.

If you have specific questions about advance care planning or advance directives, see the appendix, Questions and Answers, on page 70.

How to use this workbook

You do not have to complete the entire workbook. This workbook is designed to let you pick and choose. You can complete only the sections that are most appropriate for you, depending on your situation.

If you are healthy right now...

You will most likely want to use:

- Chapter 2: Choosing Your Spokesperson

You may also want to use:

- Chapter 3: Thinking About What Matters to You
- Chapter 5: Talking About Your Wishes

If you are living with a medical or mental health problem...

You will most likely want to use:

- Chapters 2, 3, and 5

You may also want to use:

- Chapter 6: Completing Your Advance Directive

If you have a serious medical problem that may shorten your life, if you are nearing the end of your life due to frailty and advanced age, or if for any other reason you want to plan for the possibility of your death...

You will most likely want to use:

- Chapters 2, 3, 5, and 6
- Chapter 4: Thinking About the End of Life

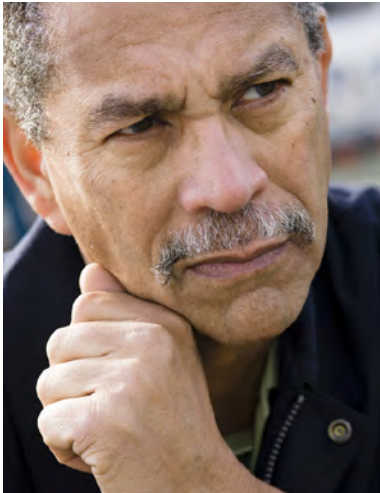
This workbook also includes:

Chapter 7: Conditions and Treatments

This chapter describes several medical conditions. These common conditions make it harder for you to participate in medical decisions. This chapter also describes life-sustaining treatments that are used frequently.

Appendix: Questions and Answers

This section answers common questions that people ask about advance care planning.



Do I have to do advance care planning?

All of these actions are voluntary. You do not need to fill out an advance directive or do any of the exercises in this workbook. However, many people have found this process to be very helpful. Advance care planning reassures them that their wishes will be known in the future. They know that these wishes will guide their loved ones and their health care providers if they can't speak for themselves.

Some people find it useful to go through this workbook with a family member. You may want to consider this approach.

Why plan ahead? One reason is that different people want different things.

You may know someone like Mr. Kingsley.

He has advanced Alzheimer's disease. He can't recognize his family anymore. He also can't do many of the things he used to do to take care of himself, like eat on his own. The aides in the nursing home lovingly care for him, and mostly he seems content.

Mr. Kingsley has developed pneumonia and needs to go to the hospital for treatment with intravenous (IV) antibiotics. His doctors say that this treatment will probably restore him to the life he had before, at least for a while. However, many people who are transferred from nursing homes to hospitals become confused and upset. Also, because Alzheimer's is a progressive disease, Mr. Kingsley's condition will keep getting worse. He may have more serious cases of pneumonia in the future, as well as other serious medical complications.

Consider the thoughts of Mr. Santini and Mr. Johnson, both deeply religious men.

Are your views similar to those of Mr. Santini?

Mr. Santini: If I'm ever in this situation, I'd want to go to the hospital for those IV antibiotics. As long as I was not in terrible pain all the time, I would want to extend my days in the nursing home for as long as possible. I want to live my life as long as I possibly can.

Are your views similar to those of Mr. Johnson?

Mr. Johnson: I can't stand the thought of being unable to recognize my family! Pneumonia might be a very peaceful way for me to pass away. I would tell my family, "Please don't send me to the hospital. Just make me comfortable in the nursing home."

Another reason is that your loved ones need your guidance.

Consider the Murphy family's story...

Dad's health had been declining for years. He had been a heavy smoker and had a lot of trouble catching his breath. He needed to wear oxygen all the time. His doctors called his condition chronic obstructive pulmonary disease, or COPD. Recently, he developed severe pneumonia. It got worse and caused an infection in his bloodstream. As a result, he needed a breathing machine and medicines to keep his blood pressure normal. He was so sick he couldn't communicate for himself. Then he slipped into a coma. This continued for three weeks.

The doctors told us that Dad's COPD was so severe he would eventually die from it. But they didn't know when that might happen. They said that patients who are very sick like Dad could get better for a while and then get sick again. The fact that Dad was so sick meant that this time might be his last. Also, if he got well enough to leave the hospital, he would probably be in worse shape than before. He would have even more trouble breathing and might even have some permanent brain damage. The doctors asked us whether Dad would want to stay on the breathing machine or to be taken off the machine and allowed to die.

I felt terrible. I didn't think Dad would want to be kept alive like this. But I knew Mom would feel guilty for the rest of her life if we told the doctors to stop the machine while there was still even the slightest hope. We weren't sure what we should do because Dad never told us what he would have wanted. I really wish we'd talked about this before.





Another reason is it may help prevent conflicts in your family.

Consider SGT Larsen’s story...

SGT Larsen is a 22-year-old Veteran. 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, which left 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 based their decision on their deep commitment to the sanctity of life. They also believed their son shared this commitment.

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 with severe disabilities. She had talked with him before he went into combat. He told her his greatest fear was getting injured so severely that he would become permanently disabled.

The doctors followed the directions from his parents because they 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.

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 can't make your own health care decisions anymore, 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.

If you are a Veteran receiving VA health care, VA will appoint a spokesperson for you from the list below. VA will start at the top of the list and work down until they find someone to be your spokesperson:

1. Health care agent (You can appoint a health care agent with a formal document called a Durable Power of Attorney for Health Care.)
2. Legal guardian or special guardian (appointed by a court)

A Durable Power of Attorney for Health Care document tells your health care providers who you want to make medical decisions for you if you get too sick to decide for yourself. It is included in the VA Advance Directive form (page 49) and most other advance directive forms.

Consider Larry Roberts...

Larry Roberts assumed his doctors would let his closest friend, Alice Jergen, make decisions about his medical treatment if he was ever unable to make them himself. She'd been visiting him daily since he had entered the final stages of lung cancer. They often talked about his wishes. But then Mr. Roberts developed an infection with a high fever, and he became confused. His doctors felt that they should talk to his next of kin before deciding whether to give him antibiotics. His next of kin was his brother Frank, who lived in another state. Frank and Ms. Jergen disagreed about what medical treatment Mr. Roberts should have. Mr. Roberts never talked about this with his brother. But because Ms. Jergen was not related to Mr. Roberts and he had not legally selected her as his spokesperson, the doctors let Frank make the decisions.

3. Next of kin. The next of kin is a relative who is 18 years of age or older. VA will contact your relatives in the following order:

- 1st: Spouse
- 2nd: Child
- 3rd: Parent
- 4th: Sibling
- 5th: Grandparent
- 6th: Grandchild

4. Close friend

If the spokesperson you would choose is different from the one that VA would choose, it is very important that you formally appoint that person as your health care agent by completing an advance directive.

If you are receiving your treatment outside of VA, the rules for choosing a spokesperson and what that spokesperson is allowed to do may be different, depending on what state you live in. You should speak to a lawyer to find out the rules in your state.

Choosing your spokesperson

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 VA 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.

Do you want to appoint a spokesperson but aren't sure who that should be? Filling in the following worksheet will help you think about the best choice for you.

Choosing a Spokesperson

Who should speak for you?

This worksheet will help you choose the best spokesperson for you. Enter the names of the people you're considering to be your spokesperson, one name at the top of each column. Your spokesperson should be a competent adult. For each person, consider each statement in the left-hand column. If the statement is true, mark the box under that person's name. If the statement is not true, leave the box blank.

You should think about how important each statement is to you when choosing the best spokesperson for you.

This worksheet is only to help you choose your spokesperson. After you choose your spokesperson, you will need to talk to that person and let other people know you have chosen that person (see page 8). You should also complete an advance directive to make your choice official (see Chapter 6, beginning on page 44).

Names of Possible Spokespersons	Name 1	Name 2	Name 3
Would be willing to speak for me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Would be able to act on my wishes instead of his/her own wishes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lives close by or could travel to be at my side if needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Knows me well and understands what's important to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Could handle the responsibility.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Will talk with me now about sensitive issues and will listen to my wishes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Would be available in the future if needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Would be able to handle conflicting opinions between loved ones and/or medical personnel.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Choosing a Spokesperson

Names of Possible Spokespersons	Name 1	Name 2	Name 3
Would be firm yet flexible when faced with confusion and changing information.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Would be able to communicate well and be clear and strong when talking with doctors or hospital officials.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other issues important to me:			
1.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thinking About What Matters to You



What matters to you?

This section presents four patients' stories. Each story illustrates a common medical condition. Because of their conditions, the patients can't make decisions about their future care anymore. As a result, each family faces difficult decisions about their loved one's care.

Each story will give you a lot to think about. You may want to share the stories and your thoughts with your spokesperson, loved ones, and health care providers.

You will also find several worksheets in this chapter. These worksheets can help you identify, think about, and express your personal wishes. You may also want to share the completed worksheets with your spokesperson, loved ones, and health care providers.



Mr. Costello's story

Frank Costello has dementia.

Dementia

People with dementia have loss of memory and other mental functions. This loss is serious enough to interfere with a person's daily activities.

Often dementia is caused by Alzheimer's disease or multiple strokes. Other things that can cause dementia are head injuries, heavy use of alcohol, AIDS, and thyroid problems. As people age, they're more likely to have dementia.

In the advanced stages of dementia, people typically don't know where they are. They usually can't recognize their own family members. Eventually they may stop eating, even with help from others.

Frank Costello is an elderly widower. He was diagnosed four years ago with Alzheimer's disease, a common form of dementia. Over time, he's been less and less able to think clearly and make decisions. Now, he doesn't remember where he is. He can no longer recognize his daughter, who visits him every day. When she visits, he seems to enjoy it when she holds his hand. For the last eight months, the nurses' aides have had more and more trouble feeding him. He's also had pneumonia several times after food has gone into his lungs. Lately, he's started to lose weight, but he doesn't seem to be hungry.

Mr. Costello has a son who thinks that his father should have a feeding tube so that he can take in liquid food and fluids. Mr. Costello's daughter is her father's appointed health care agent. She must decide whether surgeons will place a tube into her father's stomach to help provide nutrition. The surgery is quick and won't cause much pain. But the more important question is whether this is what her father wants.

Mr. Costello's doctor explained that when someone with advanced dementia loses their appetite, it is often a sign that their body is preparing for death. The doctor also said that some families choose a feeding tube, but it's important for them to know this. In people who have advanced Alzheimer's disease, feeding tubes generally don't make life last longer, prevent pneumonia, or improve function. For this reason, many doctors don't recommend feeding tubes in this situation.

Some patients in Mr. Costello's situation would want the feeding tube. Others would not. What's your view?

Some patients in Mr. Costello's situation would want the feeding tube. Others would not.

What's your view?

For additional information about dementia, see page 60.

For additional information about feeding tubes, see page 66.

Tom Rice's story

Tom Rice is in a coma.

A coma is a state of unconsciousness. Someone who is in a coma appears to be asleep and doesn't feel pain or any other sensations.

Comas can be caused by many things, including injury, illness, drug overdoses, and heart stoppage.

Some people who are in a coma will wake up and recover completely. Other people will wake up but have permanent brain damage. And others will never wake up. The longer a person stays in a coma, the higher the chance that they will have brain damage.

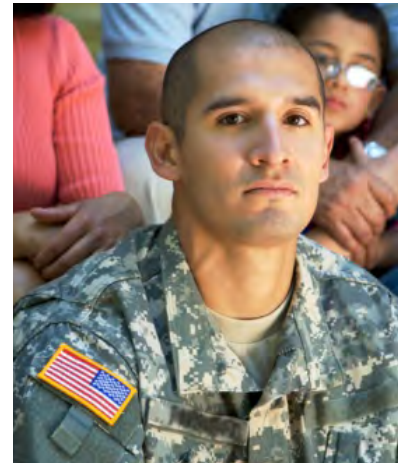
Tom Rice was 29 years old when he was hit by a car while riding his bicycle. He was taken to the hospital, where he went into a coma. He lay in bed with his eyes closed. He didn't respond when people talked to him, and he didn't wake up. He also couldn't breathe or eat on his own. Tom was put on a ventilator, or breathing machine, that pumped air into his lungs. He also had a feeding tube in his throat so that liquid food and fluids could go straight into his stomach.

Tom was single, so his doctors asked his parents to decide about his treatments. The doctors thought it was possible that Tom 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 Tom stayed in a coma, the less likely it was that he would ever wake up. And if he did come out of the coma, they said, he would probably have some brain damage. The damage could be mild, or it could be severe. Tom might need help taking care of himself and might not be able to live alone.

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

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

Coma



What would you want your parents to do?

Why?

For additional information about comas see page 58.

For additional information about ventilators see page 68.



Mrs. Parks' story

Flora Parks has had a stroke.

Stroke

A stroke is when a blood vessel in the brain is blocked or bursts, causing injury to the brain.

Strokes are the most common cause of adult disability. The disability can be mild, moderate, or severe, depending on what part of the brain is affected.

Flora Parks woke up one day and couldn't move her left arm. Her vision was blurred and she was having a hard time talking. Al, her husband of 50 years, called Mrs. Parks' doctor. The doctor thought Mrs. Parks had had a stroke and told Al to take his wife to the hospital. After a long day of tests, the hospital doctors agreed it was a stroke.

Mrs. Parks' stroke was caused by a blocked blood vessel. The doctors started her on medication and rehabilitation therapy. After a few more days, her sight improved, and she was talking clearly again. After two months, she could move her arm, but it was still a little clumsy and weak. Her therapist taught her how to make the most of her weak arm. She adjusted to her new situation, but she worried constantly about what would happen if she had a more serious stroke.

She talked about this with Al and their children. She said, "This stroke has made me think long and hard about what's important to me. The doctor said that even with my medications, I could have another stroke. If this happens, I might not be able to tell you what I want. So I'm telling you now. I love life and don't want to give up. That's why I'd be willing to go to the hospital and start rehab again to see whether I can get better. But if I get to a point where I'll never be able to communicate with you, then I don't want anything done to prolong my life. That means no CPR if my heart stops and no machines. My biggest concern is that I won't be able to talk with you or enjoy your company. I'd rather pass away quickly than suffer a long, slow decline."

For additional information about CPR see page 62.

“I understand how you feel,” Al replied, “but I think you’re only looking at the negative. Let’s think about what the children, the doctors, and I could do to make your quality of life as good as it could be, if another stroke does happen.”

If you were you in Mrs. Parks’ situation, how would you feel about your husband’s reply?

Are there things you would want your loved ones to do to improve your quality of life if you suffered a severe stroke?

Would they know what things are most important to you?

Would your loved ones know what things are most important to you?

Mr. Ruiz’s story

Mr. Ruiz has a terminal illness.

A terminal illness is a disease that can’t be cured and will eventually lead to a person’s death.

Doctors can predict that some terminal illnesses will cause death in a short period of time, such as a few weeks or months. Certain types of cancer are examples of this.

However, this isn’t true for many terminal illnesses, such as end-stage heart or lung disease. It’s nearly impossible for doctors to predict when death will occur from these illnesses. Someone with one of these diseases may suddenly get worse and die quickly or may live for a number of years.

Terminal Illness

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 pain 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?

The next set of worksheets may help you think about the things that are most important to you. These are the things that give your life special value and meaning.

If you were in this situation, would you want to go to the hospital or stay home?

My Hopes and Fears

This worksheet gives you a place to indicate your greatest hopes and fears. You can also indicate what would be meaningful or important to you if you were sick or injured and couldn't communicate for yourself.

Use this worksheet to discuss your choices with your spokesperson, loved ones, and health care providers. This worksheet will help you fill out your advance directive. As you fill in this worksheet, remember that in each situation you've lost the ability to make your own health care decisions. Using this worksheet in your advance care planning may help guide your care in these situations.

Think about each situation that the worksheet describes and write whatever comes to mind in response to the questions. You may choose to write answers for some, all, or none of the situations.

Here are some things that people might hope for:

- To get better
- To be as comfortable as possible
- To spend time with loved ones
- To have religious advisors visit
- To hear a particular type of music
- To be outside as much as possible
- To be read to
- To be massaged

Here are some things that people might fear:

- Being unable to communicate
- Being in pain
- Being separated from loved ones
- Being left out of discussions

You may attach a copy of this worksheet to your VA Advance Directive if you choose to complete one. Be sure to initial each page. If you do this, VA will treat the worksheet as part of your directive.

My Hopes and Fears

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

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

What would be your biggest fears if you were in this situation? What would you most want to avoid?

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

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

What would be your biggest fears if you were in this situation? What would you most want to avoid?

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

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

What would be your biggest fears if you were in this situation? What would you most want to avoid?

My Hopes and Fears

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

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

What would be your biggest fears if you were in this situation? What would you most want to avoid?

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

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

What would be your biggest fears if you were in this situation? What would you most want to avoid?

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

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

What would be your biggest fears if you were in this situation? What would you most want to avoid?

My Strongly Held Beliefs

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 worksheet to your VA Advance Directive if you choose to complete one. Be sure to initial each page. If you do this, VA will treat the worksheet as part of your directive.

I have religious beliefs that influence my views about 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:

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PLANNING...MY WAY

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

My Beliefs	Yes	No	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.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
I want to have my pain controlled, even if a side effect of the pain medication is that I can't think clearly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
I believe in healing through prayer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
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.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
My spokesperson should consider the financial burden of treatment on my loved ones when making health care decisions on my behalf.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
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.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Who to Contact in an Emergency

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 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.

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: _____ Other Phone: _____
 City/State/Zip: _____ E-mail: _____

Name: _____ Home Phone: _____
 Street Address: _____ Other Phone: _____
 City/State/Zip: _____ E-mail: _____

Name: _____ Home Phone: _____
 Street Address: _____ Other Phone: _____
 City/State/Zip: _____ E-mail: _____

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: _____ Other Phone: _____
 City/State/Zip: _____ E-mail: _____

Who To Contact in an Emergency

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: _____ Other Phone: _____

City/State/Zip: _____ E-mail: _____

Name: _____ Home Phone: _____

Street Address: _____ Other Phone: _____

City/State/Zip: _____ E-mail: _____

Name: _____ Home Phone: _____

Street Address: _____ Other Phone: _____

City/State/Zip: _____ E-mail: _____

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: _____ Other Phone: _____

City/State/Zip: _____ E-mail: _____

Name: _____ Home Phone: _____

Street Address: _____ Other Phone: _____

City/State/Zip: _____ E-mail: _____

Taking Care of What I Value

If you have a medical emergency or mental health crisis, you might not be able to make your own medical decisions or take care of things that matter to you. Are there certain people you'd like to care for your children, pets, or home? You can use this worksheet to discuss your choices with your spokesperson, loved ones, and health care providers. Enter contact information into the sections below that apply to you. Leave blank any sections that don't apply to you.

After completing the worksheet, initial each page and keep a copy of it with your other important papers. You should also get legal help to make sure that the people you name on this worksheet will have the legal authority to take care of your loved ones and property.

I want the following person (people) to take care of my CHILD(REN):

Name: _____ Home Phone: _____

Street Address: _____ Other Phone: _____

City/State/Zip: _____ E-mail: _____

Name: _____ Home Phone: _____

Street Address: _____ Other Phone: _____

City/State/Zip: _____ E-mail: _____

I want the following person to take care of my PET(S):

Name: _____ Home Phone: _____

Street Address: _____ Other Phone: _____

City/State/Zip: _____ E-mail: _____

I want the following person to take care of my HOME(S):

Name: _____ Home Phone: _____

Street Address: _____ Other Phone: _____

City/State/Zip: _____ E-mail: _____

I want the following person to take care of my OTHER:

Name: _____ Home Phone: _____

Street Address: _____ Other Phone: _____

City/State/Zip: _____ E-mail: _____

Mental Health Care Preferences

If you have a serious mental health condition, you should let your doctors and loved ones know your wishes for mental health care. This is just as important as letting them know your wishes for other types of medical care.

Think about your experiences with your mental health condition. If you recognize signs that your mental health is getting worse, you may want your providers and loved ones to know those signs, too. Have certain treatments or drugs helped you while others haven't? Have you been hospitalized before? If so, was it helpful? You may have had either good or bad experiences with other approaches your providers have tried, too.

You can use this worksheet to:

- Record your mental health care choices.
- Ensure that your spokesperson, loved ones, and health care providers clearly understand your wishes.

Be sure to discuss your choices with your spokesperson, loved ones, and health care providers.

You may attach a copy of this worksheet to your VA Advance Directive if you choose to complete one. Be sure to initial each page. If you do this, VA will treat the worksheet as part of your directive. Please review this worksheet with your spokesperson, loved ones, and health care providers before you attach it to your advance directive.

Talk to your legal advisor if you want to use a state-authorized mental health advance directive. Your advisor can help you incorporate your preferences onto that document.

This worksheet has four parts:

- Mental Health Symptoms
- Medication and Treatment Preferences for Mental Health
- Entering a Mental Health Facility
- Other Information and Preferences

Mental Health Symptoms

The signs that my mental health condition may be getting worse include:

Mental Health Care Preferences

Medication and Treatment Preferences for Mental Health

I prefer to receive the following medications, therapies, and other treatments (if indicated) because they helped me when my symptoms were worse:

If reasonable alternatives exist, I would like to avoid the following treatments. Identify the reasons for your preferences, such as bad side effects, concern about long-term side effects, or that the medication didn't work when your symptoms were worse:

I understand that medications may cause side effects. However, if there are reasonable alternatives, I especially would like to avoid the following bad side effects.

Check up to four:

- Unusual movements of my mouth or other areas
- Numbness (loss of sensation)
- Motor restlessness (not being able to sit still or stand without moving around)
- Seizures (In a seizure, your body twitches or shakes for a brief period of time. You can't control your body and you usually become unconscious.)
- Stiffness in my muscles or body, so that I can't move my arms, legs, or body smoothly or normally
- Tremors (An example of a tremor is when your hands shake or vibrate very fast and you can't control it.)
- Nausea or vomiting (feeling sick to your stomach or throwing up)
- Gaining weight
- Losing weight
- Diabetes (Diabetes is a condition that causes problems maintaining your normal level of blood sugar. It's sometimes called the "sugar disease.")
- Problems with my sexual functioning
- Addiction or dependence on the medication(s)
- Other:

Mental Health Care Preferences

Entering a Mental Health Facility

If I need serious and short-term (acute) emergency mental health care because I can't take care of myself, I prefer that my doctors consider an alternative to hospitalization. Examples of these alternatives are acute follow-up, mental health case management, and prompt follow-up with an outpatient mental health provider.

Yes (Name or describe the alternative(s).)

No

If I need to be hospitalized for mental health problems, I prefer to be in the following programs/facilities. Identify the reasons for your preferences:

Program/Facility:	Reason:
Program/Facility:	Reason:
Program/Facility:	Reason:

Mental Health Care Preferences

I prefer NOT to be admitted to the following mental health programs/facilities. Identify the reasons for your preferences:

Program/Facility:	Reason:
Program/Facility:	Reason:
Program/Facility:	Reason:

Mental Health Care Preferences

Other Information and Preferences

The staff of the hospital or crisis unit should know that the following things might help me get my mental health symptoms under control:

The staff should know that the following things might help me relax and be less agitated, and also might lessen the need to restrain me and keep me by myself (in seclusion):

I have these additional preferences for my mental health treatments:

Thinking About the End of Life



These four worksheets will help you think about other things, like:

- Would or wouldn't you want life-sustaining treatments and when?
- How do you want to spend your last days?
- Have you thought about donating your organs or having an autopsy after you die?
- Do you want to leave instructions for whether your body should be buried or cremated, or for a funeral or memorial service?

For most of us, it's hard to think about the end of life. But many people feel strongly about what would be important to them at the end of their lives. For example, many people who would otherwise die can be kept alive with life-sustaining treatments. These treatments often prolong a person's life. However, they don't cure illness or heal injury. Some people only need life-sustaining treatments for a short period of time and then they recover. Other people never come off of these treatments.

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 first worksheet in this section will help you think about this question for yourself.

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

Section 1

In this section, you can express your general views about life-sustaining treatments.

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 ideas about how they want to live, people also have different ideas about how they want to die. 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:

- 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

Section 2

In this section, you can express your treatment preferences for specific medical situations.

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 health care 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?

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.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Explanation (i.e., comments, clarifications):			
If I have permanent, severe brain damage that makes me unable to recognize my family or friends (for example, severe dementia).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Explanation (i.e., comments, clarifications):			
If I have a permanent condition where other people must help me with my daily needs (for example, eating, bathing, toileting).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Explanation (i.e., comments, clarifications):			

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

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 need to use a breathing machine and be in bed for the rest of my life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Explanation (i.e., comments, clarifications):			
If I have pain or other severe symptoms that cause suffering and can't be relieved.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Explanation (i.e., comments, clarifications):			
If I have a condition that will make me die very soon, even with life-sustaining treatments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Explanation (i.e., comments, clarifications):			
Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Explanation (i.e., comments, clarifications):			
Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Explanation (i.e., comments, clarifications):			

My Last Days

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 worksheet to your VA Advance Directive if you choose to complete one. Be sure to initial each page. If you do this, VA will treat the worksheet as part of your directive.

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

More information:

Organ Donation and Autopsy

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 VA 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)

Yes No Not Sure

If you choose "yes" you should:

- Fill out an organ donor card
- Tell your loved ones

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

Yes No Not Sure

Would you allow an autopsy? (Check one)

Yes

Yes, but with the following limitations: _____

No

Not Sure

Burial and Funeral Arrangements

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 and your health care providers.

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 scattered or 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. Check with your local VA medical center for information on burial and memorial benefits offered to veterans.

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, such as:

- Where it should be held
- Songs or readings to include
- Where donations should be sent
- Information for your obituary notice
- Other wishes

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, you still need to talk 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 say what you want thoroughly and clearly.

This chapter covers the following:

- Who you should talk to
- How to start the conversation
- What to talk about
- Why you should talk with your health care providers
- What to say to your health care providers



MR. NAKAMURA TALKS WITH HIS DAUGHTER...

Kenji Nakamura wanted to appoint his daughter Suzy to be his spokesperson. The first time he tried to talk to her about this, she said, “Dad, you’re going to live to be 100 years old! We don’t need to talk about this now.” The next time she came over, he eased into the conversation by talking about the things he was thankful for, like his health. Then he asked her to look at the statement of his wishes that he’d been writing. Suzy was surprised to learn that her dad didn’t ever want machines to keep him alive. She said, “What if you needed a breathing machine for only a few days?” After talking about it, they both had a better understanding of his wishes. He didn’t want to be kept alive on a breathing machine forever, but it would be OK for a short time.

Who you should talk to

You should definitely talk to your **spokesperson**. But there may be other people you should talk to as well. Think about the people who are important to you. Then try to imagine being seriously ill or injured and unable to communicate. Who would you want to be involved at such a time? These are the people you should share your feelings with now. This can help prevent confusion, conflict, and hurt feelings later.

In addition to your spokesperson, you might also want to talk to:

- Family members
- Health care providers
- Other caregivers
- Friends
- Spiritual advisor(s)

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 from this workbook that got your attention, it may also get the attention of the people you want to talk to. Share the story with them. 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.



You could start by saying,

“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.”

ADDITIONALLY YOU COULD USE A LETTER, TAPE, OR VIDEO RECORDING.

It may be easier for people to hear what you have to say at first if you aren’t there. So you could ask them to read a personal letter, listen to a tape, or watch a video in which you express your feelings and wishes. Afterward, they may be more ready to sit down and talk with you.



Encourage your spokesperson to decide as they think you would.

What to talk about

1. Asking someone to be your spokesperson

When you ask someone to be your spokesperson, you're asking them to take on a big responsibility. You and your spokesperson both want to be comfortable with this. You don't want this person to agree to be your spokesperson if they really have strong doubts about it.

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 decide as they think you would.

2. Telling others about your spokesperson

Once your spokesperson has agreed, you should let your loved ones know that you have chosen a spokesperson and tell them who that person is. 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 [he/she] 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 the copy of your advance directive.

3. Your beliefs

If you couldn't speak for yourself, what would be meaningful or important to you? The worksheets titled *My Hopes and Fears* (page 17) and *My Strongly Held Beliefs* (page 20) will help you think about and talk about these things. The worksheet *My Last Days* (page 34) will help you discuss what is important to you at the very end of your life.

4. Life-sustaining treatments

Life-sustaining treatments are medical treatments that keep you alive for a while but don't cure you or make you better. Use the worksheet *When I Would or Wouldn't Want Life-Sustaining Treatments* (page 31) to help you express your views.

5. Your mental health care preferences

If you have a serious mental health condition, you may want to use the worksheet *Mental Health Care Preferences* (page 25) to record your views and to help you talk with your spokesperson, family members, and close friends.

6. Who to contact

You may have specific preferences for certain people you want your health care providers to contact—or not to contact—if you have a medical emergency or a mental health crisis. You can use the worksheet *Who to Contact in an Emergency* (page 22) to discuss your preferences.

7. What you value

You may have specific preferences for who you would like to care for your children, pets, home, and so on if you are unable to do so. You can use the worksheet *Taking Care of What I Value* (page 24) to guide your discussion.

8. What you want to happen after your death

The worksheets *Organ Donation and Autopsy* (page 35) and *Burial and Funeral Arrangements* (page 36) will help you think about and discuss what you want to happen after you die.





Why you should talk with your health care providers

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

- Your doctor, nurse, social worker, chaplain, and other health care providers 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, what might happen to you, and how to ensure that your wishes are honored.
- You can't assume that your health care providers truly understand your values and preferences unless you talk to them.
- Your health care providers need to know who you want as your 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 mean. 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 talk about this to make sure that you have their attention.

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 just file your advance directive in your chart without discussing it! 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 worksheets you completed from this workbook. 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?”

“Can I count on you to follow my wishes 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?”



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 directives are written instructions that tell your health care providers who 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 the mental health (or psychiatric) advance directive. A mental health advance directive is for patients with mental health problems that might interfere with their ability to make health care decisions.

In this directive, you may indicate your preferences for your future mental health care, such as for hospitalization or medications.



In VA, there are three options for creating a mental health advance directive:

- Some states have a special form and/or regulations for a mental health advance directive.
- You may indicate your preferences for mental health care in Part III, Section B, of your VA Advance Directive.
- You may complete the *Mental Health Care Preferences* worksheet in Chapter 3 and attach it to your VA Advance Directive. When you do this, the worksheet becomes part of your directive.

Types of advance directives

There are several different types of advance directives, which are described below. The type of advance directive that is right for you depends on where you receive your medical care.

Which advance directive is right for me?

All of these documents are legally binding within the VA health care system, unless they conflict with clinical or professional standards or VA policy.

Outside of the VA health care system, 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.

You might receive care from VA but live in a state that doesn't recognize the VA Advance Directive. If this is the case, VA encourages you to complete both a VA document and a document that is legally binding in your state. Make sure the two documents are consistent with each other. This makes sure that you have a legal advance directive if you end up in a hospital outside of the VA system.

Some states have a special form and/or regulations for a mental health advance directive.



VA Advance Directive

The VA Advance Directive contains:

- A Durable Power of Attorney for Health Care
- A Living Will

The VA Advance Directive contains more detail than most other advance directive documents. It also allows you to attach worksheets and other documents. This lets you provide a more complete understanding of your wishes. Also, you don't need a lawyer to fill out a VA Advance Directive to use within VA.

A VA Advance Directive may or may not be legally binding outside of the VA health care system. This depends on your state's laws.

Department of Defense advance directive

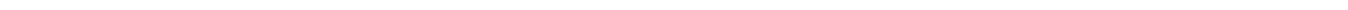
This is an advance directive that a military lawyer drafts for military personnel. It's legally binding in VA and in every state. It isn't affected by the restrictions of any state laws.

State advance directive

This is any advance directive that is legally binding under a certain state's laws.

Most states recognize both a Durable Power of Attorney for Health Care and a Living Will. Some states require you to use a particular form. Other states have restrictions about language. These states say that you must or must not include certain language in your advance directive. Other states are more like the VA health care system because they recognize many kinds of written documents.

If you wish to complete a state advance directive, check with a lawyer or local legal services organization to determine the requirements in your state.



Completing your VA Advance Directive

The VA Advance Directive is an official document where you can write down your preferences about your medical care. It has five parts:

- Part I: Personal Information
- Part II: Durable Power of Attorney for Health Care
- Part III: Living Will
- Part IV: Signatures
- Part V: Signature and Seal of Notary Public (optional)

Which parts of the advance directive form should I complete?

You may choose to complete just the Durable Power of Attorney for Health Care section. You can also choose to complete only the Living Will section.

If you have someone you trust to make decisions on your behalf, VA recommends 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. If you want to give specific instructions, you can also complete the Living Will section. If you want, you can provide additional information by attaching the worksheets that you completed in this workbook.


If you have questions, discuss this with your health care provider. Remember to tell your loved ones what you've chosen.

Current copies of the VA Advance Directive form can be found at:
<http://www.ethics.va.gov/docs/VAAD.pdf>

Keep your advance directive up to date.

It's a good idea to review your advance directive from time to time. This is because your values and preferences for health care may change when you get older or when your health condition changes.





Review your advance directive when major changes happen.

How often should I review my advance directive?

Your circumstances affect when and how often you review your advance directive. **But it's important to review your advance directive even if you're healthy.**

When 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. If this happens to you, you may want to take another look at your advance directive and review *Thinking about the End of Life* on page 30.

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



VA ADVANCE DIRECTIVE DURABLE POWER OF ATTORNEY FOR HEALTH CARE AND LIVING WILL

This advance directive form is an official document where you can write down your preferences for your health care. If someday you can't make health care decisions for yourself anymore, this advance directive can help guide the people who will make decisions for you.

You can use this form to:

- Name specific people to make health care decisions for you
- Describe your preferences for how you want to be treated
- Describe your preferences for medical care, mental health care, long-term care, or other types of health care

When you complete this form, it's important that you also talk to your doctor, family, and other loved ones who may help to decide about your care. You should explain what you meant when you filled out the form.

A health care professional can help you with this form and can answer any questions that you have. If you need more space for any part of the form, you may attach extra pages. Be sure to initial and date every page that you attach.

PART I: PERSONAL INFORMATION

NAME (<i>Last, First, Middle</i>):		LAST FOUR DIGITS OF SSN:
STREET ADDRESS:		
CITY, STATE, ZIP:		
HOME PHONE WITH AREA CODE:	WORK PHONE WITH AREA CODE:	MOBILE PHONE WITH AREA CODE:

Privacy Act Information and Paperwork Reduction Act Notice

The information requested on this form is solicited under the authority of 38 C.F.R. §17.32. It is being collected to document your preferences for your health care in the event that you can't speak for yourself anymore. The information you provide may be disclosed outside the VA as permitted by law. Possible disclosures include those that are described in the "routine uses" identified in the VA system of records 24VA10P2, Patient Medical Records-VA, published in the Federal Register in accordance with the Privacy Act of 1974. This is also available in the Compilation of Privacy Act Issuances. You may choose to fill out this form or not. But without this information, VA health care providers may not understand your preferences as well. If you don't fill out this form, there won't be any effect on the benefits you are entitled to receive. The Paperwork Reduction Act of 1995 requires us to let you know that this information collection follows the clearance requirements of section 3507 of this Act. We estimate that it will take you about 30 minutes to fill out this form, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the information you write down. A Federal agency may not conduct or sponsor, and a person is not required to respond to a collection of information, unless it displays a current valid OMB control number. The OMB Control No. for this information collection is 2900-0556.

VA ADVANCE DIRECTIVE: DURABLE POWER OF ATTORNEY FOR HEALTH CARE AND LIVING WILL

NAME (Last, First, Middle)

LAST FOUR DIGITS OF SSN:

PART II: DURABLE POWER OF ATTORNEY FOR HEALTH CARE

This section of the advance directive form is called a Durable Power of Attorney for Health Care. It lets you appoint a specific person to make health care decisions for you in case you can't make decisions for yourself anymore. This person will be called your Health Care Agent.

Your Health Care Agent should be someone:

- You trust
- Who knows you well
- Who is familiar with your values and beliefs

If you get too sick to make decisions for yourself, your Health Care Agent will have the authority to make all health care decisions for you. This includes decisions to admit and discharge you from any hospital or other health care institution. Your Health Care Agent can also decide to start or stop any type of health care treatment. He or she can access your personal health information, and medical records, including information about whether you have been tested for HIV or treated for AIDS, sickle cell anemia, substance abuse or alcoholism

NOTE: If you wish to give general permission for VA to share your medical records or health information with others, you can complete VA Form 10-5345 (Request for and Authorization to Release Medical Records or Health Information). You can get VA Form 10-5345 from your VA health care provider or you can get it using a computer from this website <http://www4.va.gov/vaforms/medical/pdf/vha-10-5345-fill.pdf>.

A - HEALTH CARE AGENT

Place your initials in the box next to your choice. Choose only one.

Initials

I don't wish to appoint a Health Care Agent right now.
(Skip this section and go to Part III, Living Will.)

Initials

I appoint the person named below to make decisions about my health care if I can't decide for myself anymore.

Name (Last, First, Middle):

Relationship to Me:

Street Address:

City, State, Zip:

Home Phone with Area Code:

Work Phone with Area Code:

Mobile Phone with Area Code:

VA ADVANCE DIRECTIVE: DURABLE POWER OF ATTORNEY FOR HEALTH CARE AND LIVING WILL

NAME (Last, First, Middle)	LAST FOUR DIGITS OF SSN:
----------------------------	--------------------------

B - ALTERNATE HEALTH CARE AGENT

Fill out this section if you want to appoint a second person to make health care decisions for you, in case the first person isn't available.

Initials	If the person named above can't or doesn't want to make decisions for me, I appoint the person named below to act as my Health Care Agent.
----------	--

Name (Last, First, Middle):	Relationship to Me:
-----------------------------	---------------------

Street Address:	City, State, Zip:
-----------------	-------------------

Home Phone with Area Code:	Work Phone with Area Code:	Mobile Phone with Area Code:
----------------------------	----------------------------	------------------------------

PART III: LIVING WILL

This section of the advance directive form is called a Living Will. This section of it lets you write down how you want to be treated in case you aren't able to decide for yourself anymore. Its purpose is to help others decide about your care.

A - SPECIFIC PREFERENCES ABOUT LIFE-SUSTAINING TREATMENTS

In this section, you can indicate your preferences for life-sustaining treatments in certain situations. Some examples of life-sustaining treatments are:

- CPR (cardiopulmonary resuscitation)
- a breathing machine (mechanical ventilation)
- kidney dialysis
- a feeding tube (artificial nutrition and hydration)

Think about each situation described on the left and ask yourself, "In that situation, would I want to have life-sustaining treatments?" Place your initials in the box that best describes your treatment preference. **You may complete some, all, or none of this section. Choose only one box for each statement.**

	Yes. I would want life-sustaining treatments.	I'm not sure. It would depend on the circumstances.	No. 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.	Initials	Initials	Initials
If I have permanent, severe brain damage that makes me unable to recognize my family or friends (for example, severe dementia).	Initials	Initials	Initials

VA ADVANCE DIRECTIVE: DURABLE POWER OF ATTORNEY FOR HEALTH CARE AND LIVING WILL

NAME (*Last, First, Middle*)

LAST FOUR DIGITS OF SSN:

	Yes. I would want life-sustaining treatments.	I'm not sure. It would depend on the circumstances.	No. I would not want life-sustaining treatments.
If I have a permanent condition where other people must help me with my daily needs (for example, eating, bathing, toileting).	Initials	Initials	Initials
If I need to use a breathing machine and be in bed for the rest of my life.	Initials	Initials	Initials
If I have pain or other severe symptoms that cause suffering and can't be relieved.	Initials	Initials	Initials
If I have a condition that will make me die very soon, even with life-sustaining treatments.	Initials	Initials	Initials
Other:	Initials	Initials	Initials

B - MENTAL HEALTH PREFERENCES

This section is optional. You may skip this section if you do not have a serious mental health problem or if you do not want to write down your preferences for mental health care. If you have a serious mental health condition, you might want to write down medications that have worked for you in the past and that you would want again, or you might want to write down the mental health facilities or hospitals that you like and those that you don't like. If you need more space, you may attach extra pages and use this space to refer to attached pages. Be sure to initial and date every page that you attach.

VA ADVANCE DIRECTIVE: DURABLE POWER OF ATTORNEY FOR HEALTH CARE AND LIVING WILL

NAME (*Last, First, Middle*)

LAST FOUR DIGITS OF SSN:

C - ADDITIONAL PREFERENCES

This section is optional. In this space, you can write other important preferences for your health care that aren't described somewhere else in this document. For example, these might be social, cultural, or faith-based preferences for care, or preferences about treatments such as feeding tubes, blood transfusions, or pain medications. If you need more space, you may attach extra pages and use this space to refer to attached pages. Be sure to initial and date every page that you attach.

D - HOW STRICTLY YOU WANT YOUR PREFERENCES FOLLOWED

Place your initials in the box next to the statement that reflects how strictly you want others to follow your preferences. Choose only one.

Initials

I want my preferences, as expressed in this Living Will, to serve as a **general guide**. I understand that in some situations, the person making decisions for me may decide something different from the preferences I express above, if they think it's in my best interests.

Initials

I want my preferences, as expressed in this Living Will, to be followed strictly, even if the person making decisions for me thinks that this isn't in my best interests.

VA ADVANCE DIRECTIVE: DURABLE POWER OF ATTORNEY FOR HEALTH CARE AND LIVING WILL

NAME (*Last, First, Middle*)

LAST FOUR DIGITS OF SSN:

PART IV: SIGNATURES

A - YOUR SIGNATURE

By my signature below, I certify that this form accurately describes my preferences.

SIGNATURE

DATE

B - WITNESSES' SIGNATURES

Two people must witness your signature. VA employees may be witnesses if they are members of:

- The Chaplain Service
- The Social Work Service
- Nonclinical employees (e.g., Medical Administration Service, Voluntary Service, or Environmental Management Service)

*Other employees of your VA facility may **not** sign as witnesses to your advance directive unless they're in your family.*

Witness #1

I personally witnessed the signing of this advance directive. I am not appointed as Health Care Agent in this advance directive. I am not financially responsible for the care of the person making this advance directive. To the best of my knowledge, I am not named in the person's will.

SIGNATURE:

DATE:

Name (*Printed or Typed*):

Street Address:

City, State, Zip:

Witness #2

I personally witnessed the signing of this advance directive. I am not appointed as Health Care Agent in this advance directive. I am not financially responsible for the care of the person making this advance directive. To the best of my knowledge, I am not named in the person's will.

SIGNATURE:

DATE:

Name (*Printed or Typed*):

Street Address:

City, State, Zip:

VA ADVANCE DIRECTIVE: DURABLE POWER OF ATTORNEY FOR HEALTH CARE AND LIVING WILL

NAME (*Last, First, Middle*)

LAST FOUR DIGITS OF SSN:

PART V: SIGNATURE AND SEAL OF NOTARY PUBLIC (*Optional*)

This VA Advance Directive form is valid in VA facilities without being notarized. However, you may need to have it notarized to be legally binding outside the VA health care setting. Space for a Notary's signature and seal is included below.

On this _____ day of _____, in the year of _____, personally appeared before me _____, known by me to be the person who completed this document and acknowledged it as their free act and deed. IN WITNESS WHEREOF, I have set my hand and affixed my official seal in the County of _____, State of _____, on the date written above.

Notary Public _____ Commission Expires _____

[SEAL]

Wallet Card

It's a good idea to keep this card in your wallet. This card will notify your health care providers about the people and documents they should consult in case of an emergency.

Instructions:

Make a copy of this page, enter your information, and then sign it. Then cut out the card and put it in your wallet. You can use a copy machine to make it smaller, and you may want to have your card laminated.

ATTENTION HEALTH CARE PROVIDERS

I have a Durable Power of Attorney for Health Care.

I have a Living Will.

I have another advance directive document (specify): _____

My Health Care Agent is:

The document(s) are located:

Name:

Address:

Signature: _____

City, State, Zip:

Date: _____

Phone:

Please consult this person and/or these documents in case of an emergency. The people or institutions that have copies of these documents are listed on the back of this card

My alternate Health Care Agent is:

Name:

Address:

City, State, Zip:

Phone:

Wallet Card

ATTENTION HEALTH CARE PROVIDERS

People or institutions that have copies of these documents are:

Conditions and Treatments



This chapter describes two conditions that could leave you unable to make your own medical decisions:

- Unconsciousness (coma and vegetative state)
- Dementia

This chapter also explains four common treatments used for different medical problems:

- CPR
- Dialysis
- Feeding tube
- Ventilator

CAUSES:

Many things can cause a coma or a vegetative state, including:

- Injury
- Illness
- A drug overdose
- A stopped heart

Unconsciousness, coma and vegetative state

What is it?

A coma is a state of unconsciousness in which you look like you're sleeping. If you're in a coma, you don't move much. You usually show no signs of pain or distress.

Some people who are in a coma move into a vegetative state. A vegetative state is another state of unconsciousness.

If you're in a vegetative state, you may open your eyes and look like you're awake. But you're really unconscious because you don't have any sensation or awareness. If you're in a vegetative state, you may make movements like yawning, smiling, or pulling back your arms or legs. Or you may look like you're watching something or responding to someone. But really, these movements are reflexes. They're not under your control.

According to expert medical opinion, a person who is in a coma or a vegetative state:

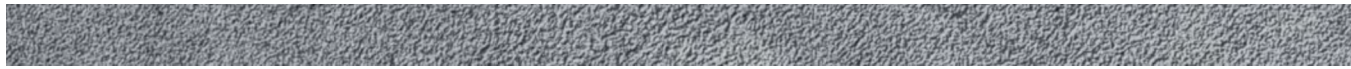
- Doesn't feel pain or any other sensations
- Has no awareness
- Can't interact in any way with the world around them

What's it like?

What would I feel and understand?

People who've come out of a coma or a vegetative state usually say that they don't have any memory or awareness of the time that they were unconscious. These people usually say that they don't remember any pain or discomfort.

A few people say that they were aware of things going on around them, or that they heard what people said near them. These people weren't really unconscious.



How would people take care of me?

If you were in a coma or a vegetative state, you'd probably be cared for in a hospital or nursing home. This is because other people would need to do all of your personal care for you, including:

- Feeding you through a tube
- Cleaning up your body wastes
- Turning you every few hours to prevent bedsores

Some patients in a vegetative state are cared for at home by their loved ones.

What's likely to happen?

It would be very hard to say what would happen to you just after you went into a coma. For example:

- Some people wake up and recover completely.
- Other people never wake up.
- Other people have permanent brain damage.

In general, the longer you stay in a coma, the higher the chance that you won't come out of it. If you stay in a coma for a long time, you have a higher chance of severe brain damage.

If you stay in a vegetative state for a long time, experts refer to this as a permanent vegetative state. This occurs after:

- More than three months (when your vegetative state is caused by illness)
- More than a year (when your vegetative state is caused by injury)

At that point, your chances of recovery are nearly zero.

For an example of someone in a coma, see Tom Rice's story on page 13.

CAUSES:

One of the most common causes of dementia is Alzheimer's disease.

Another common cause is multiple strokes.

Other things can also cause dementia. Examples are Parkinson's disease, heavy alcohol use, AIDS, and thyroid problems.

Dementia**What is it?**

Dementia is a condition in which you lose your mental skills, such as:

- Memory
- Thinking
- Talking
- Problem solving

It's normal to lose some mental skills with old age. But if you have dementia, this loss is severe enough to interfere with your daily life.

Anyone can get dementia. Dementia is more common in older people. By age 85, about one out of every seven people has dementia.


What's it like?

The most common kinds of dementia get worse over time.

An example is Alzheimer's disease. The problem usually starts with minor memory problems. Over time, your memory problems would get worse. You might get new problems, such as difficulty concentrating or getting confused easily.

As your condition got worse, you might have major personality changes:

- Some people lose interest in things around them.
- Other people become agitated.
- Other people seem happy almost all the time.



Eventually, you'd start to need help with your daily activities, like dressing and bathing. Later, you might become less active and less talkative, although you might continue to enjoy other people's company.

In the final stages of Alzheimer's disease, you'd lose your ability to speak, walk, control your bladder or bowels, and swallow.

If you had dementia, you might be aware that you had a problem at first. As the dementia got worse, you would become totally unaware of your problem.

What's likely to happen?

Some types of dementia can be treated and even cured. An example is dementia that's caused by thyroid problems. However, most types of dementia get worse over time and never get better.

If your dementia couldn't be treated, you might lose your mental skills over many years. Or you might lose them more quickly. In Alzheimer's disease, severe dementia usually occurs within five to ten years after the first memory loss. Severe dementia generally leads to death from complications, such as infections.

For an example of someone with dementia, see Frank Costello's story on page 12.



CPR

What is it?

CPR stands for cardiopulmonary resuscitation. It's sometimes used in an emergency when someone's heart has stopped beating adequately. Cardiac arrest is another term for when the heart stops beating.

If you're in cardiac arrest, blood stops flowing through your body. This means that oxygen can't get to your brain. Your brain can survive without oxygen for only about five minutes. After that point, you'd have permanent brain damage.

CPR makes a small amount of blood and oxygen flow to your brain while doctors or emergency medical personnel try to get your heart to beat normally again. This helps prevent brain damage.

CPR may include:

- Someone pushing up and down on your chest with their hands (chest compressions)
- Artificial breathing. This might mean that someone breathes from their mouth into yours (mouth-to-mouth). Or, someone might use a small bag attached to a mask to push air into your lungs.
- Someone giving you drugs to stimulate your heart
- A machine giving you a quick electrical shock to your chest (defibrillation)
- Someone putting a tube into your windpipe (intubation)

If CPR gets your heart to beat normally again, but you don't start breathing on your own, you might be put on a breathing machine (mechanical ventilator).

When would I need it?

You'd only get CPR if you had a cardiac arrest.

Cardiac arrest can be expected or unexpected. If your doctor told you that you would die soon, cardiac arrest would be expected as part of the normal dying process. Cardiac arrest could happen unexpectedly if you had a heart problem or if you were in critical condition because of a sudden illness or injury.

If you're in a hospital and you go into cardiac arrest, hospital staff will automatically do CPR, unless you have a do-not-attempt-resuscitation (DNAR) order. A DNAR order tells doctors, nurses, and emergency medical personnel not to do CPR if you go into cardiac arrest.

Without it...

If you have cardiac arrest, you'll lose consciousness and pass out quickly. Once you pass out, you won't feel anything. If you don't receive CPR, you'll die in about five to ten minutes.

With it...

When CPR works, you may recover completely and may go on to live for many years. This outcome occurs more often when you have a cardiac arrest due to an easily treatable rhythm problem with your heart and CPR is begun very soon after the cardiac arrest. In other cases, however, CPR is far less effective. CPR is not very effective when cardiac arrest is caused by a serious illness that cannot be reversed, or when CPR is not started within five minutes after a cardiac arrest. For example, since many hospitalized patients are seriously ill, only about one in six patients who receives CPR in the hospital ends up surviving their hospital stay.

Some people who survive after getting CPR recover completely. Others have serious complications because they didn't get enough blood to their vital organs while their hearts weren't beating adequately.

Pros

CPR can save lives, especially when it's given to a young, healthy person right after cardiac arrest.

When CPR is successful, it may return the person to the same health that they were in before their heart stopped.

The person generally isn't aware of the procedure because the person isn't conscious during CPR.

Cons

CPR is often unsuccessful, especially when it's given to someone who has a very serious or incurable disease.

Most hospitalized patients who get CPR don't survive to leave the hospital.

After CPR, some people have a sore chest or broken ribs because of the chest compressions. Some people also have permanent brain damage because they didn't receive enough oxygen to their brain despite CPR.



Dialysis

What is it?

Dialysis is a medical procedure that filters your blood to remove waste products when your kidneys can no longer do the job. Dialysis is a type of life-sustaining treatment.

There are two main types of dialysis: hemodialysis and peritoneal dialysis.

In **hemodialysis**, your blood circulates outside of your body into a machine that removes waste products. A needle is inserted into one of your blood vessels. The needle is attached to a tube that carries a steady flow of your blood into the machine. After the machine removes waste products, your blood returns to your body through a second needle that is inserted into another blood vessel nearby.

In **peritoneal dialysis**, your blood is filtered by the blood vessels in the lining of your abdomen (peritoneum). A fluid that's washed in and out of your abdomen helps to filter your blood. The fluid flows through a tube that's inserted into a hole made on your abdomen. You usually can receive peritoneal dialysis at home.

Hemodialysis is the more common type of dialysis. Peritoneal dialysis isn't an option for everyone. To have peritoneal dialysis, you must be able to do it yourself at home or have someone who can do it for you.

When would I need it?

People who have severe problems with their kidneys use dialysis. If your kidneys stop working, waste products build up in your bloodstream. This will make you feel sick to your stomach, tired, and weak. You'll have little appetite and will have swelling. You might also have difficulty breathing or thinking clearly. Dialysis helps relieve these symptoms.

Dialysis Pros & Cons

Without it...

If your kidneys stop working completely, and you don't receive dialysis, you die, usually within a week or two. First, you feel sick. Then you probably feel sleepy or get short of breath. In the end, you go into a coma and aren't aware of anything around you. Eventually, your heart stops.

If your kidneys stop working and you don't receive dialysis, you'll receive care to keep you as comfortable as possible.

With it...

To get hemodialysis, you usually have to be in a hospital. You can also travel to a dialysis clinic on a regular schedule, usually three times per week. If there's someone who can be trained to give you hemodialysis, there's a small chance that this person can give it to you at home. During each hemodialysis session, you sit in a chair next to a big machine. Each session usually lasts about four hours.

With peritoneal dialysis, you can give yourself treatments at home, at work, or even while traveling. You need to have the equipment with you. Fluid from a bag flows into your abdomen through a tube. It stays there for several hours, then drains out through the tube and is thrown away. Normally, this repeats several times each day.

Pros

Dialysis usually prolongs your life.

Dialysis can allow you to lead a near-normal life. You should be able to go back to work and participate in many activities that you enjoy. Dialysis can also relieve many of the uncomfortable symptoms that are associated with kidney failure.

If you are eligible for a kidney transplant, dialysis can keep you alive while you wait for a donor.

Cons

Dialysis can't do as good a job as your kidneys. As a result, waste products and fluids build up in your body between dialysis sessions. At times, you may not feel well.

The time you spend on dialysis may interfere with your daily or weekly routine. It may also limit your ability to travel. If you have dementia or are confused, dialysis may be frightening.

You'll have to be careful about the types of food you eat. You may also be more likely to get infections, bleeding, and other medical problems. You may get tired easily.



Feeding Tube

What is it?

A feeding tube carries liquid nutrition and fluids into your stomach or intestines.

One kind of tube goes into the nose, through the throat, and into the stomach. This is called a nasogastric tube. It's about one-eighth of an inch in diameter.

Another kind of tube goes through your skin into your intestines. This tube requires minor surgery. The operation is quick and safe. You won't feel much discomfort. Once the tube is in place, it's usually painless.

When would I need it?

A feeding tube is sometimes used when people have trouble swallowing enough food and water. If you're having trouble swallowing, you'll usually eat less. Therefore, you won't receive proper nutrition. There is also a danger that food can "go down the wrong pipe." This means that you inhale food into your lungs. You might have trouble swallowing if you're very sick, have brain damage, or have a medical problem that affects your nerves or muscles.

Feeding Tube Pros & Cons

Without it...

If you don't get enough nutrition, you lose weight, feel weak, and are more likely to get sick. If you don't receive any fluids or nutrition at all, you die, usually within about three weeks. At first you might feel hungry or thirsty. But this feeling usually lasts for only about three days. You'll probably be given ice chips and mouth swabs to keep your lips moist. Eventually, you'll go into a coma. After that, you're not aware of what's going on, and in a few days you'll die.

With it...

If you're awake and aware of what's going on, having a tube down your nose and throat is somewhat uncomfortable. But you'll get used to it. It's usually not painful. The tube through your stomach wall isn't painful, either, and you can hide it under your clothes. When liquid is flowing through the feeding tube, it makes it harder for you to get around. If you get confused or agitated, you might pull on the feeding tube. To prevent this from happening, you might be given medication to make you sleepy or you might have your hands restrained.

Pros

A feeding tube might prolong your life and let you live for years. This depends on your condition.

A feeding tube can provide all the fluid and nutrition your body needs.

You don't need to be in a hospital to receive fluid and nutrition through a feeding tube.

With proper nutrition, you're less likely to get bedsores and other complications.

Cons

If you have advanced cancer or severe dementia, a feeding tube probably will not prolong your life and could even shorten it due to complications.

You might inhale liquid into your lungs with a feeding tube. This would cause pneumonia.

You would have a tube attached to your nose or your stomach.



Ventilator

What is it?

A ventilator is a machine that helps you breathe. Ventilators are also called mechanical ventilators, breathing machines, and artificial respirators.

A ventilator works by pushing air and oxygen into your lungs. A tube is placed in your windpipe. It's put through your mouth or nose or through a hole in your neck (tracheotomy). The tube is about three-fourths of an inch in diameter, which is about the size of a dime.

When would I need it?

A ventilator breathes for you if you can't breathe well enough on your own. You may need it if you have:

- Severe lung problems
- Brain damage
- Spinal paralysis
- Severe weakness of the muscles in your chest

You might need a ventilator for a few hours, a few days, or the rest of your life. At first, it may be impossible to tell how long you might need it.

Ventilator Pros & Cons

Without it...

Some people with life-threatening illnesses choose not to use a ventilator to prolong their lives. Instead, they choose to let nature take its course. If you choose not to use a ventilator, you'll receive care to keep you as comfortable as possible instead. You'll be offered medications to help you relax so that you don't feel like you have to struggle for breath. If your lungs fail and you decide not to use a ventilator, or if you're on a ventilator and decide to stop, you'll probably die within minutes. However, you may live for several hours. Sometimes, doctors think a person needs a ventilator, but that person unexpectedly survives for several days, or even longer.

With it...

You generally can't talk if you have a tube down your nose or mouth into your windpipe. If you have a tracheotomy, you can often learn to talk, although it's not easy.

Some people who use a ventilator can get around in specially equipped wheelchairs and live long and productive lives.

Most patients on a ventilator can't get out of bed and are in a hospital. Usually, they're in an intensive care unit. Other patients on a ventilator can go to a nursing home or be cared for at home. If you're not awake or alert, you might pull on the tube. To prevent this from happening, you might need to take medication to make you sleepy or have your hands restrained.

Pros

A ventilator often prolongs your life when you might otherwise die.

You might need it for only a short time. For example, you may need a ventilator only while your body recovers from a serious illness.

If you're awake and aware of what's going on, a ventilator is uncomfortable. However, you'll get used to it. It usually isn't painful. In some cases, it can relieve the discomfort of feeling breathless.

Some people who need a ventilator live for years and lead productive and satisfying lives.

Cons

You might need the ventilator for the rest of your life.

You might not be able to talk.

You might have to stay in bed.

You'll have a tube attached to your nose, mouth, or throat.

You'll need a lot of help. For example, someone will probably need to suction your lungs to keep them clear of mucus. This help might come from family members, close friends, or nurses.

Questions and Answers

Q: *Why should I complete an advance directive?*

A: Advance directives are legal documents that help you guide your health care decisions if you get too sick to make decisions for yourself. Advance directives can help your spokesperson or loved ones make important health care decisions on your behalf by letting them know your values and preferences.

Q: *When does an advance directive go into effect?*

A: Only when you aren't able to make your own health care decisions anymore.

Q: *Why should I appoint a spokesperson?*

A: There are lots of reasons. See Chapter 2, Choosing Your Spokesperson.

Q: *How do I appoint a spokesperson?*

A: Choose a spokesperson, talk to that person, and fill out a Durable Power of Attorney for Health Care. See Chapter 2, Choosing Your Spokesperson.

Q: *What happens if I don't appoint a spokesperson?*

A: Health care providers will consult someone close to you. They'll usually contact your next of kin, starting with your spouse. If you're married and want your spouse to be your spokesperson, then you probably don't need a Durable Power of Attorney for Health Care. If you're separated from your spouse but not divorced, health care providers will still ask your spouse to make decisions for you, unless you've appointed someone else as your spokesperson.

Q: *Does the VA honor a common law spouse or a civil union spouse in choosing a spokesperson?*

A: Not necessarily. It's best to appoint this person as your legal spokesperson through a Durable Power of Attorney for Health Care. This will make sure that they'll be able to make decisions for you if you can't communicate your own decisions anymore.

Q: *Can a friend be my spokesperson?*

A: Yes, but unless you appoint your friend as your spokesperson using a Durable Power of Attorney for Health Care, your health care providers may not consult your friend. Or, your friend may be overruled by your family members. See Chapter 6, Completing Your Advance Directive.

Q: *What happens if some family members don't agree with my spokesperson about what's best for me?*

A: Generally, the spokesperson gets to decide. However, disagreements could delay decisions about your treatment while health care providers try to sort things out and reach agreement about what to do. It could also cause bad feelings in your family. The best way to prevent disagreements is to communicate with everyone ahead of time to let them know who you've picked and what you want.

Q: *What if I don't know anyone who I want to be my spokesperson?*

A: Your best choice is to complete a Living Will and give a copy to your health care providers. You can also complete additional forms, such as the worksheets in this book, to give more information about your values and preferences.

Q: *Do I need to talk to my spokesperson now?*

A: Yes, because you need to make sure they're willing to be your spokesperson. It's also important to tell them about your wishes so they'll know what to do for you.

Q: *How do I communicate information about my values and preferences?*

A: Think about what matters to you (see Chapter 3). Then, talk to your spokesperson, loved ones, and health care providers (see Chapter 5). You may also want to write down more detailed information about your values and preferences, using some of the worksheets in this book (see Chapters 3 and 4). If you want, you can also complete a Living Will. See Chapter 6, Completing Your Advance Directive.

Q: *What should I do with my advance directive after I've signed it?*

A: You should give a copy to each person who you want to know your wishes, including your spokesperson and your health care providers. Keep a list of their names. Put the original document in a place where others can easily find it. Don't put your only copy in a safe-deposit box. It may not be easy to get if someone needs it. You can also fill out a wallet card to let people know about your advance directive.

Q: *What if I change my mind about what I want after I've completed my advance directive?*

A: You can always change your directive. The best approach is to destroy the old one and write a new one. Be sure to give revised copies to everyone who has a copy of your older version.

Q: *What advance directive form should I use?*

A: There are several types of advance directives, including VA, state, and Department of Defense advance directives. See Chapter 6, Completing Your Advance Directive.

Q: *VA's form includes a Durable Power of Attorney for Health Care and a Living Will. Do I need to fill out both parts of the VA form?*

A: No. It's up to you whether you complete the Durable Power of Attorney for Health Care, the Living Will, or both. See Chapter 6, Completing Your Advance Directive.

Q: *I have homes in two states. Is my advance directive valid in both places?*

A: States often have different laws and different forms. Check with your health care providers or legal advisors in each place. However, a VA Advance Directive is valid throughout the VA system. See Chapter 6, Completing Your Advance Directive.

Q: *What do I need to do to make sure my advance directive is a legal document?*

A: In general, you need to sign your advance directive and have it witnessed. Follow the instructions on the form, and check with a local lawyer to make sure your directive qualifies as a legal document outside of VA. The VA form is legal throughout the VA health care system, and no lawyer is required.

Q: *What types of advance directives are legal in VA?*

A: VA recognizes all types of legal advance directives including VA Advance Directives, state advance directives, and Department of Defense advance directives. It does not matter what state you are in if you are within the VA system. See Chapter 6, Completing Your Advance Directive.

Q: *Outside of VA, will my advance directive be legal in all 50 states?*

A: The laws vary from state to state. However, most states will recognize an advance directive from another state. If you have a home in more than one state, check with your health care provider or a legal advisor in each state. One form might work for all places, or you may need to complete a form to use in each state. A VA Advance Directive is valid throughout the VA system, no matter where your facility is located. A VA Advance Directive may or may not be legally binding outside of VA, depending on state law. But it still can carry a lot of weight in medical decisions by informing your providers and others about your preferences. See Chapter 6, Completing Your Advance Directive.

Q: *Will my VA Advance Directive be honored outside the VA?*

A: It depends on state law. You should talk to your health care providers or legal advisors about this. They may recommend that you fill out both a VA Advance Directive and a state advance directive. See Chapter 6, Completing Your Advance Directive.

Q: *Do health care providers have to follow my advance directive?*

A: Your advance directive provides important guidance for your spokesperson and health care providers. Your spokesperson will choose your treatment based on the advance directive and all of the other information they have about your case. Generally, your advance directive should be followed, unless there is conflicting information about your wishes. In a few cases, advance directives can't be followed because they conflict with legal or professional standards.

Q: *What if my family members or providers disagree about how to interpret my directive?*

A: All VA health care facilities and most non-VA facilities have an Ethics Consultation Service that can help resolve conflicts. Talking with your spokesperson, loved ones, and health care providers ahead of time can help to prevent future conflicts.

Q: *Is withdrawing treatment the same as assisted suicide?*

A: No. All competent adult patients in the United States have the legal right to accept or refuse treatments of any kind. When death results from not providing a life-sustaining treatment or stopping a life-sustaining treatment, it's not considered a suicide or assisted suicide.

Q: *Can I specify that I want assisted suicide in my directive?*

A: No. Assisted suicide isn't an option that you can request through an advance directive. Assisted suicide is illegal throughout the VA health care system, even in states where assisted suicide is legal.



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