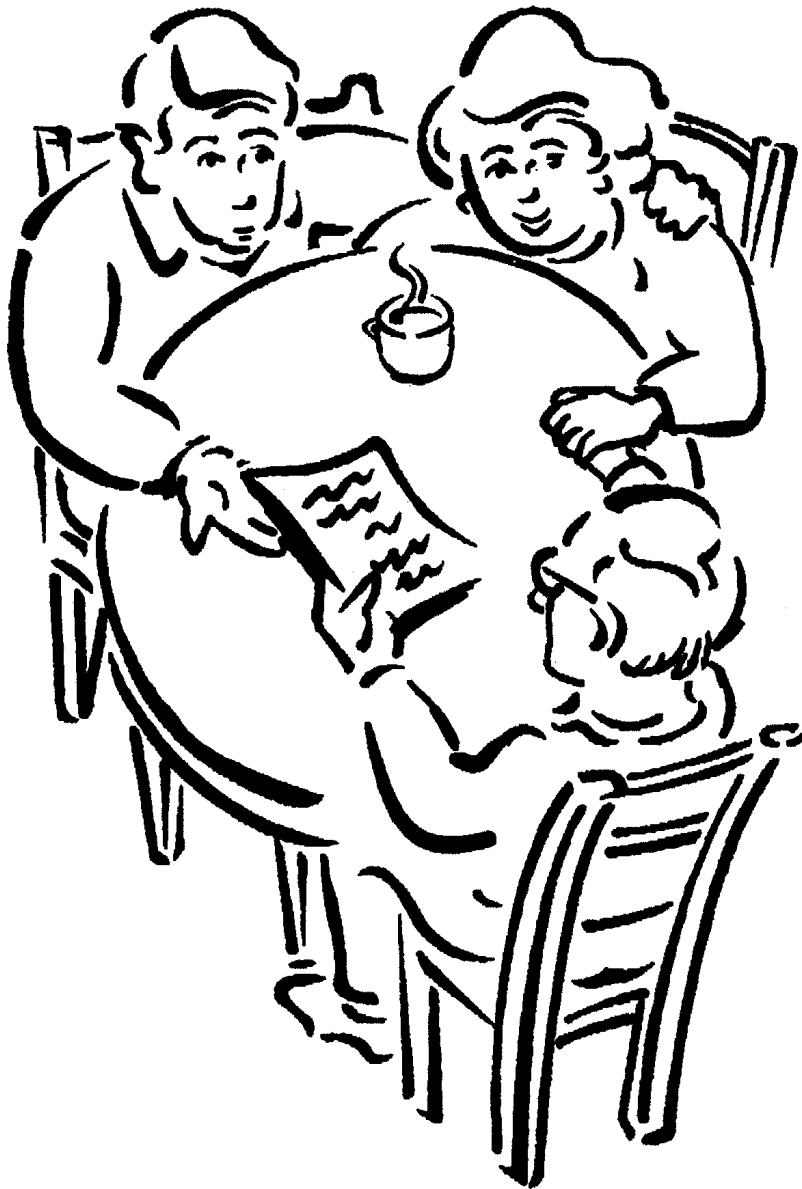


*Your Life, Your Choices:  
Planning for Future Medical Decisions*

Note –

**The following is a 1997 publication that was produced under VA IIR Grant No. 94-050, “Development of an Advance Care Planning Workbook,” 4/01/95 – 3/31/97. The document is currently undergoing revision for release in VA. The revised version will be available soon.**

# **Your Life Your Choices**



**Planning  
for Future  
Medical  
Decisions:**

**How to  
Prepare a  
Personalized  
Living Will**

# Your Life Your Choices

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*Planning for  
Future Medical  
Decisions:*

*How to Prepare  
a Personalized  
Living Will*

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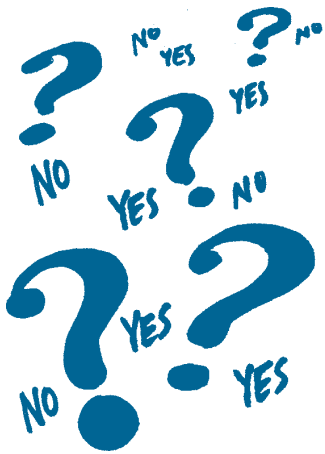
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"What should we do for Dad?"

**"We got the kind of call we'd feared."** Dad had been in declining health for months. Then he fell asleep at the wheel and was in a bad car accident. Three weeks later he was still in a coma. A breathing machine pumped air into his lungs because he could not breathe on his own. The doctors thought his chances of coming out of the coma were slim. They talked with Mom and me about turning off the breathing machine and allowing Dad to die naturally. 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 "pull the plug" 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."

## Your Life, Your Choices

There's only one person who is truly qualified to tell health care providers how you feel about different kinds of health care issues—and that's you. But, what if you get sick, or injured so severely that you can't communicate with your doctors or family members? Have you thought about what kinds of medical care you would want? Do your loved ones and health care providers know your wishes?

Many people assume that close family members automatically know what they want. But studies have shown that spouses guess wrong over half the time about what kinds of treatment their husbands or wives would want.

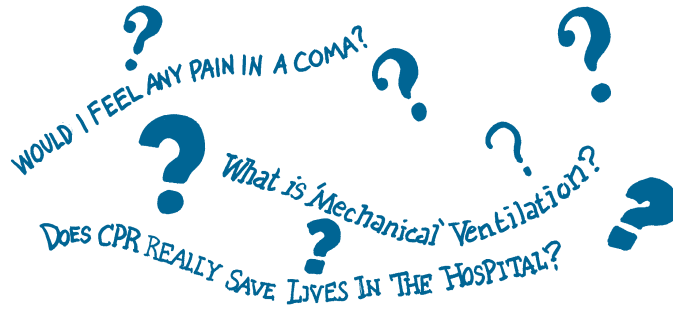
You can help assure that your wishes will direct future health care decisions through the process of *advance care planning*.

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# What do you need to do to guide your future health care?

## 1. Figure out what you want.

**Think.** You need to understand what kinds of situations you might face and the options for care.



## 2. Communicate this to others.

**Talk.** Tell your loved ones and health care providers about your strongly-held beliefs and what kinds of care you would want in different situations.



**Write.** Write down your wishes so your loved ones will have a record of what you told them. This also helps if no one is around who can speak for you.



*Forms are included in the back of this workbook. It can take as little as 15 minutes to fill them out.*

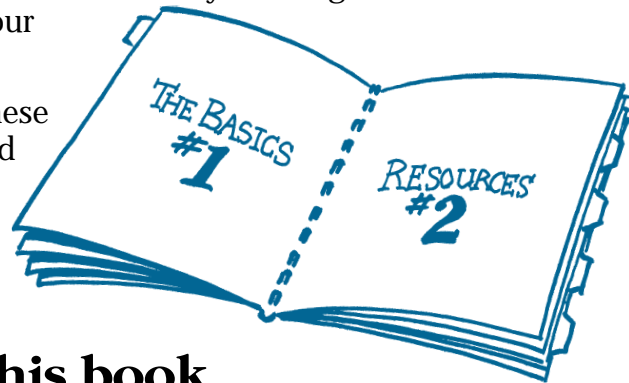
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## How to use this workbook.

This workbook has two parts.

**Part I: The Basics.** This 14-page section introduces and discusses all of the important components of advance care planning. You may find it provides enough information for you to figure out what you want and express your wishes to others.

**Part II: Resources.** Turn to these sections for additional help and further explanation of ideas and topics introduced in “The Basics.”



## Two ways to use this book.

Spend an hour working through “The Basics.” Then communicate.



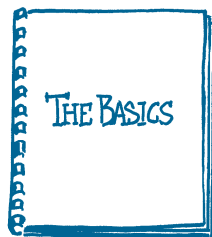
COMMUNICATE

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OR

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Work through “The Basics.” Take another hour or two to work through all or part of “Resources” for a more complete approach. Then communicate.



COMMUNICATE

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## Why do you need to think *now* about future health care decisions?

Whether you are young or old, healthy or sick, there may come a time when an important decision needs to be made about your health care. And whether it's tomorrow or five years from now, there's no guarantee that you will be able to express your wishes for yourself at that time. Consider the Larsen family:

**Chris Larsen never told his family** what kind of medical measures he'd want if he became critically ill. He is in a nursing home after having suffered a severe stroke 9 months ago. He is paralyzed and unable to take care of himself or communicate in any way. Now he has pneumonia and will probably die unless he goes to the hospital to receive intravenous antibiotics. He also may need to be on a breathing machine for a week or so. The doctor says that his chances of returning to normal are remote, but that he has a fair chance of getting over the pneumonia. His family members disagree about what they should do. His son Bill says, "Dad was never a quitter. He'd want to fight to the very end, as long as there was the slightest hope." His daughter Trudy disagrees. "Sure, Dad wasn't a quitter, but he wanted to die naturally—he would be horrified to be kept alive this way."

In fact, Trudy's views were the closest to Mr. Larsen's true opinion. But the family never had a way to find this out. They treated his pneumonia and he lived another year in the nursing home without recovering his ability to communicate or care for himself.

This story shows why it is so important to discuss your wishes. Talking with your family and health care providers ahead of time can prevent confusion and help ease the burden on them.

## Do you have any strongly-held beliefs that should guide your care?

Think ahead. Imagine being in a critical condition—one in which you were unable to communicate your wishes. If medical decisions could mean the difference between life and death, what would you want your loved ones and health care providers to do?

Your strongly-held beliefs can guide these choices because they help others understand what you value about life. But be sure to explain your beliefs because people often use the same words to mean very different things. Consider the cases of Mrs. Santini and Mrs. Johnson, both deeply religious women.

**"I want to be kept alive as long as possible,"**

Maria Santini has said on many occasions. "Life is sacred and has meaning, no matter what its quality."

**"When my time comes, keep me comfortable."**

Irene Johnson also believes life is sacred. However, she has often said, "I've lived a long and full life. I don't want anything done just to keep me alive."

Because Mrs. Santini and Mrs. Johnson both believe that life is sacred, many people would assume that their views on being kept alive would be the same. But, as you've seen, it's not that simple.

Here's another example. Have you ever heard anyone say, "If I'm a vegetable, pull the plug"? What does this mean to you? What's a vegetable? What's a plug? Even people who live together can have very different ideas about what the same words mean without knowing it. The story of May and John Williams shows how important it is to be specific about what you mean.



When you say, "pull the plug" it could mean a variety of things:

- Stop the breathing machine
- Remove the feeding tube
- Don't give me antibiotics
- Stop everything

**"I'd never want to live like a vegetable." Both**

May & John Williams have always shared this belief during their fifty years of marriage. But when they were talking about their advance care plans, they learned that they had very different views about what that meant. For May, it's when she can't take care of herself. John was surprised. For him, being a "vegetable" is much worse. "It's when my brain's not working but my body is being kept alive by machines."

People have very different notions of what it means to be a "vegetable." Here are some more examples:

- "You sit in a chair and don't do anything all day."
- "You can't read anymore."
- "You're just a body with some life in it."

## **If you couldn't speak for yourself, what would you want done for you?**

Think about the following statements. Do you agree with any of them? Discussing your answers with others can help them understand what is important to you and where you stand with respect to health care decisions.

My life should be prolonged as long as it can, no matter what its quality, and using any means possible.

I believe there are some situations in which I would not want treatments to keep me alive.

I'd want my religious advisors to be consulted about all medical decisions made on my behalf to make sure they are in keeping with my religious teachings.

My personal wishes would not be as important as what my family thinks is best for me.

I'd want to have my pain controlled, even if the medications make me sleepy or make it difficult to have conversations with my family.



*Pages 21-26  
have exercises  
to help you  
specify your  
beliefs and  
values in more  
detail.*

## Who will speak for me if I can't speak for myself?

For people with close family members, choosing a spokesperson may seem simple. If you are married, your health care providers will ask your spouse to speak for you. If you are not married, other relatives usually are consulted. However, if these people disagree, it can be very difficult for health care providers to know whom to listen to.

Sometimes your closest next-of-kin is NOT the person you would like to speak for you. In that case, you can formally appoint the person of your choice to be your "voice." You can give this person the legal authority to make health care decisions for you using a "durable power of attorney for health care." The following story shows why this is so important.

### Larry Roberts assumed his doctor would listen

to his closest friend, Mrs. Alice Jergen, for advice about his wishes for medical treatment. She'd been visiting him daily since he entered the final stages of lung cancer and they talked about it often. Three days ago, he developed an infection and became delirious with a high fever. Before making a decision about whether to start him on antibiotics, Mr.

Roberts' doctor felt it was appropriate to consult his next-of-kin. This turned out to be his brother Frank, who lives in another state. Frank and Mrs. Jergen disagreed about what medical treatment Mr. Roberts should have. Mr. Roberts never talked about this with his brother. But because Mrs. Jergen was not related to Mr. Roberts and had no legal authority, the doctor followed his brother's advice.



A durable power of attorney for health care ensures that the right person will speak for you when you can't speak for yourself.

## Common questions about choosing a spokesperson.

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

**A:** Health care providers will consult with someone close to you. They will usually contact your next-of-kin, starting with your spouse. If you are married and want your spouse to be your proxy, then doing nothing is probably OK. If you are separated from your spouse but not divorced, health care providers will still ask your spouse to make decisions for you.

**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, he or she may not be consulted or may be overruled by family members.

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

**A:** Health care providers usually will give treatment while they try to reach agreement about what to do. 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:** *Who is the best person to be my spokesperson?*

**A:** Think about the people in your life and ask yourself the questions below.

- Who knows me well?
- Who would do a good job representing me?
- Who is available to come to my side if needed?

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

**A:** Your best choice is to write down your wishes and give a copy to your health care provider. Fill out a legal form, such as a living will, with as much detail as possible. Include a personalized statement, such as the exercises from this book, to provide a better understanding of your wishes.

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

**A:** Yes, because you need to make sure they are willing, and to tell them about your wishes so they'll know what to do for you.



If you are married, your spouse will be recognized as the person to make decisions on your behalf, unless you have a durable power of attorney for health care that appoints someone else.



See page 20 if you need more help deciding who is the best person to be your spokesperson.

## What else can I do to make my wishes known?

It is good idea to write down your wishes for future health care because it gives others the most complete picture of how you feel and what you would want. You can do this by signing an **advance directive**, which can be either a formal, legal document or an informal statement of your wishes. There are two types of formal directives: proxy and instructional.

A **proxy directive** uses a legal document called a “durable power of attorney for health care” to appoint a spokesperson who can make health care decisions on your behalf. It goes into effect when health care decisions need to be made for you and you can’t communicate or make health care decisions for yourself.

**Instructional directives**, such as a “living will” or “directive to physicians,” are written instructions to physicians in the event you cannot speak for yourself. They usually tell health care providers which treatments you would not want if you become *terminally ill* or end up in a *permanent coma*.

A **personalized statement** lets you express what is most important to you. In addition to talking with loved ones and health care providers, you can make this statement by including the exercises from this workbook, writing a letter to your loved ones, or making an audio or video tape.

There are 3 steps to advance care planning:

1. Think through your preferences
2. Talk about your wishes with others
3. Document your wishes

Completing an advance directive or writing a personalized statement are ways to accomplish the third step.



You can personalize your advance directive with exercises from this workbook, a letter, or even a tape.

## Which directive is best?

It depends on your situation. You could complete either a proxy or instructional directive, both, or just a personal statement. Most health care providers like proxy directives best because it means they will have someone to talk with who knows you well. But not everyone has a proxy to represent them. In that case, an instructional directive will help your health care providers decide what’s best for you. Either way, adding a personalized statement helps others feel more confident that they are doing what you would have wanted them to do.

## Common questions about advance directives.

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

**A:** Advance directives are legal documents that help you keep control over future health care decisions. They can also relieve your loved ones of the burden of making life and death decisions on your behalf.

**Q:** *When do advance directives go into effect?*

**A:** Only if you become unable to understand your medical treatment options or are unable to communicate your wishes for medical treatment.

**Q:** *What's the difference between a "living will" and a regular will?*

**A:** A living will, like all advance directives, is restricted to decisions about your health care. It goes into effect while you are still alive but unable to communicate. A regular will pertains to your estate and property. It goes into effect after your death.

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

**A:** You should give a copy to each person whom you want to be informed of your wishes, including your health care providers. Keep a list of their names. Put the original in a place where others can easily find it. Do *not* put your only copy in a safe-deposit box because it may not be easy to get if someone needs it. You can also fill out the wallet card (in the back) to let people know where they can find a copy.

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

**A:** You can always change your directive. Either write the changes on your existing directive (initial and date the changes), or 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:** *I have homes in 2 states. Is my advance directive valid in both places?*

**A:** States often have different laws and different forms. It may be best to complete separate forms for each state. Check with your health care providers in each place.



Blank copies of advance directive forms are located in the back pocket of this workbook.



## What situations and decisions do people commonly face?

There are many situations in which people are not able to talk or communicate their wishes because of illness or injury. The following stories describe the kinds of decisions family members, friends and health care providers must make when people can't speak for themselves. As you read these stories, try to think about how you would value the quality of your life in each situation and whether you would make the same kinds of decisions for yourself.

### Dementia

Lily Chen, an elderly widow, was diagnosed 4 years ago with Alzheimer's disease, a common form of **dementia**. Over time she has gradually been losing her ability to think clearly and make decisions. Now she doesn't remember where she is and she can no longer recognize her daughter who visits her every day. For the last 8 months, she has been completely dependent on nurse's aides to bathe and feed her. Recently, she stopped eating altogether. Her daughter has power of attorney for health care and has to decide whether to have a **long-term feeding tube** surgically placed into her mother's stomach. The surgery is quick and won't cause much pain, but the real issue is guessing how Mrs. Chen would value her current life. If they place the feeding tube, Mrs. Chen could live for many more years in the same or worse condition. If they don't, she will die in about 2 weeks or less, and probably won't feel hungry or thirsty.

- *The percent of people with dementia increases with age. At age 65, it's about 5%, at age 75, it's 10-20%, and at age 85, it's about 35%.*
- *With Alzheimer's disease the mind fails before the body—many people are otherwise healthy.*
- *In the advanced stages of dementia, people typically do not know where they are or recognize family members. They frequently stop eating, even with help from others.*

Go to "More information about health conditions and treatments" for greater detail. See page 29 for **dementia**, page 34 for **feeding tube**, page 28 for **coma (and PVS)**, and page 35 for **ventilator**.



#### Questions to consider:

Do you think Mrs. Chen's daughter should decide about the feeding tube based on the fact that her mother isn't eating, or based on her mother's memory problems and dependence on others for care? Why?



## Coma

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

Tom was single so his parents were asked to decide whether to continue the treatments that were keeping him alive. His doctors thought Tom might come out of it but that it could take anywhere from one week up to a year. They said that the longer Tom remained in a coma, the less likely it was that he would ever wake up. They thought that if he did come out of the coma, he would probably have severe brain damage. He would need help taking care of himself and would not be able to live alone.

Tom had never said anything about what he would want if he were in an accident. His parents kept him "hooked up" for weeks and weeks to give him every chance. After 2 months, they decided it was hopeless since he hadn't changed in all that time. They stopped all treatment and Tom died that same day.

- *People in a coma don't feel pain or any other sensations.*
- *Comas can be caused by injury, illness, drug overdoses and heart stoppage. Predicting the outcome of coma depends on what caused it, how long the person has been in coma, and age.*
- *Doctors say that it can take 3-4 weeks to see whether a person will come out of coma or go into a related condition, "persistent vegetative state" or **PVS**.*

### Questions to consider:

Do you think Tom's parents kept him alive long enough? Too long? Why do you feel this way?

What if Tom were 69 instead of 29? Would it make a difference? Why?

## Stroke

Flora Park woke up one day and couldn't move her left arm. Her vision was blurred and she was having difficulty talking. Her husband called her doctor who told her to go to the hospital—he suspected a **stroke**. After a long day of tests, the doctors agreed it was a stroke. They 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 ways to make the most of her weak arm. She was adjusting to her new situation, but she worried constantly about what would happen if she had a more serious stroke.

She talked about this with her husband 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 and 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 feed myself or do anything on my own, then I don't want anything done to prolong my life. That means no **CPR** if my heart stops and no machines. My biggest fear is that I won't be able to talk with you or enjoy your company. I'd rather die quickly than suffer a long, slow decline."

- *Risk factors for stroke include being over age 55, high blood pressure, heart disease, diabetes, smoking, high cholesterol and family history.*
- *Stroke is the #1 cause of adult disability. Impairments can be mild, moderate or severe, depending on what part of the brain is affected.*
- *Most recovery of lost sensations or function occurs within the first 3-6 months after a stroke.*
- *People who've had a stroke have a 5-10% chance of having another one. The first few months after their first stroke is the time when they are at greatest risk.*

### Questions to consider:

Do you share Mrs. Park's views about when she wouldn't want treatment to prolong her life?

For you, is there such a thing as unacceptable quality of life? Where would you draw the line?



See page 30 for more on **stroke**, page 33 for **CPR**, page 31 for **terminal illness** and page 36 for **hospice**.

## *Terminal illness*

Carlos Ruiz had severe heart disease for years. His doctor said, "Your heart is much worse and it will continue to get weaker. Now we need to make some decisions about your goals for care. One approach would be to concentrate on supporting your heart, lung and other vital organs to extend your life as long as possible. Another option would be to make relief of pain and discomfort our highest priority, even if it meant you might not live as long. Which of these approaches sounds right for you?"

Mr. Ruiz said, "I've lived with this bad heart for a long time. I'm tired of fighting, but I'm not quite ready to give up. I'd try simple treatments, especially if I can be at home with my family. I'd rather be comfortable than live a long time."

Mr. Ruiz' doctor gave him a referral to a **hospice** nurse who started visiting him at home. He got a few lung infections which made it hard to breathe. He cured them by taking antibiotic pills at home. Then he got another infection that didn't get better, despite taking antibiotic pills. He had a high fever and was so sick that his wife had to decide what to do. His doctor and hospice nurse said they could put him in the hospital to treat his infection which would relieve his symptoms and might prolong his life. Or he could stay at home with additional comfort measures until he died.

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

- With **terminal illness**, the underlying disease can no longer be cured. Most people with a terminal illness are expected to die within 6 months.
- **Comfort care** includes medications for pain and other symptoms, and keeping the person clean and dry. Sometimes treatments such as blood transfusions, antibiotics, or chemotherapy are used to provide comfort by relieving symptoms.
- People who are close to death often go "in and out" of awareness, being alert only part of the time.

### **Questions to consider:**

Do you agree with Mrs. Ruiz's decision to send her husband to the hospital? Do you think she followed his wishes?

## Telling others what you want.

Your loved ones and health care providers need to know how you feel if they are to carry out your wishes in the future.

Raising this topic is not always easy. If your family members and friends are uncomfortable talking or even thinking about these issues, consider these ideas to get a discussion started:

- Begin on a positive note by talking about how much you value them and their willingness to listen to you.
- Share one of the stories from this workbook to show how planning in advance can ease the burden on family members.
- Remind them that accidents can happen to anyone at any time and that you just want to be prepared.

Including others in a discussion about what you want can also help clarify your wishes in your own mind. Consider the story of Mr. Nakamura:

### 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, including 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 never wanted to be kept alive by machines. She said, “What if you only needed a breathing machine for a few days?” After talking about it they both had a clearer understanding of his wishes — he didn’t want to be kept alive on a ventilator *forever*, but a short time would be OK.



*For more ideas about ways to start a conversation about your wishes or what to talk about, turn to page 45.*



*Blank advance directive forms are located in the back pocket. The exercises throughout this workbook can be used to personalize these forms.*

## Writing it down.

Even if you've talked about your wishes, when the time comes, stress and strong emotions can cause your loved ones to forget what you told them or wonder if they are making the right decision. A written document can help keep things straight.

You may document your preferences formally using advance directives. If you want to fill out either a proxy and/or instructional directive, the forms are in the back of this workbook.

Some people are more comfortable documenting their wishes informally in a letter or an audio or video tape. It seems more personal. You can also personalize formal advance directives by attaching these informal statements or any of the exercises from this workbook.

Either way, "writing it down" means you've left a record of your wishes that everyone—family, friends, and health care providers—can use as a general guide or as explicit instructions. You won't have to worry that your wishes will be forgotten or misunderstood.

"What you say is in the air, what you write is always there."



### Suzy was glad her dad had written his wishes

down when Mr. Nakamura fell and broke his hip. While he was in the hospital, he got pneumonia and became confused. His doctors asked Suzy whether they should put him on a ventilator if he had trouble breathing. She shared his advance directive with the doctors and explained her father's fears of being kept alive forever by a machine. As a result, they decided to start antibiotic treatment, and if needed, they would put Mr. Nakamura on a breathing machine for only a short period of time. If he didn't seem to be improving, they would stop the breathing machine and focus their attention on keeping him comfortable. Suzy was thankful that her father had insisted on discussing his wishes.

## What's Next?



### Talk about it...

Now that you've read through "The Basics" of advance care planning, you may feel ready to talk about your wishes with your family and health care providers. If you need help starting the conversation, see pages 46 to 50 for some ideas.

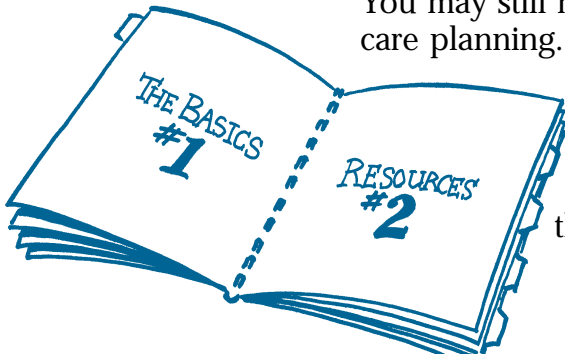
### Write about it...

Sometimes it helps to have a few thoughts on paper. Try pulling out the forms in the back of the book and filling them out. Don't worry about making them perfect—there are two sets of forms so you can always go back and finalize your thoughts. The important thing is to get started.



### Learn more...

You may still have some questions about advance care planning. The "Resources" sections that follow are designed to give you a better understanding of specific topics. You can refer to only the sections that concern you, or read it straight through—whichever works for you.



Here's a sample of the kinds of questions that are answered in the Resources section:

- What makes life worth living?
- What's likely to happen if you have a serious stroke? What do you need to think about in advance?
- What if someone you love needs a feeding tube? What are the pros and cons?
- What can you do to keep the courts out of these advance care planning decisions?



### For more details:

➡ see page 21

➡ see page 30

➡ see page 34

➡ see page 51

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## Thought-provoking exercises.

### Which exercises should I complete?

You can complete any or all of them. Each of the exercises addresses different issues, including:

1. What to consider when choosing a spokesperson (page 20),
2. Your wishes regarding what makes life worth living (page 21),
3. Your personal and spiritual beliefs that affect medical decision making, and your feelings about hope and risk taking (pages 22-23),
4. Your wishes regarding the way you might spend your last weeks or days if you were dying, and other related matters (pages 24-26).

We recommend that you complete at least the exercises on pages 21-24. These will be the most useful to others if they have to make decisions for you.

You may want to ask your religious advisor to help you think through the questions about quality of life, medical interventions, and death and dying. Religions have different philosophies about what to do under the situations described in these exercises.

### I don't like writing in books. Besides, I'm not ready to write down my answers. What should I do?

We have included a copy of these exercises in the back of the workbook. You can use these to draft your ideas.

### What should I do with these exercises once I've completed them?

- Use them to discuss your values with your loved ones and health care providers.
- Attach them to your advance directive as your personal statement. They will provide greater details about your wishes.
- Put your initials and date on each page so others will know when you filled them out.
- Review them each year — your answers could change with time.

## Choosing A Spokesperson

Initials & Date: \_\_\_\_\_

### Who should speak for me?

**Instructions** This exercise will help you choose the best spokesperson for you. On the top of each column, write in the names of one or more people you're considering to be your spokesperson. Place a check mark (✓) in the column for that person if the following statements are true. The first two statements must be true for your spokesperson to have legal authority to represent you. You should weigh how important the other attributes are to you in deciding your first choice.

	Names		
<b>Meets the legal criteria in my state for durable power of attorney for health care</b> (see the instructions in the back pocket).			
<b>Would be willing to speak on my behalf.</b>			
Would be able to act on my wishes and separate her/his own feelings from mine.			
Lives close by or could travel to be at my side if needed.			
Knows me well and understands what's important to me.			
Could handle the responsibility.			
Will talk with me now about sensitive issues and will listen to my wishes.			
Will be available in the future if needed.			
Would be able to handle conflicting opinions between family members, friends, and/or medical personnel.			
Other issues important to me:  _____  _____  _____			



Initials & Date: \_\_\_\_\_

## What makes your life worth living?

**Instructions** This exercise will help you think about and express what really matters to you. For each row, check (✓) one answer to express how you would feel if this factor by itself described you.

Life like this would be:

	difficult, but acceptable	worth living, but just barely	<u>not</u> worth living	can't answer now
a. I can no longer walk but get around in a wheelchair.				
b. I can no longer get outside—I spend all day at home.				
c. I can no longer contribute to my family's well being.				
d. I am in severe pain most of the time.				
e. I have severe discomfort most of the time (such as nausea, diarrhea, or shortness of breath).				
f. I rely on a feeding tube to keep me alive.				
g. I rely on a kidney dialysis machine to keep me alive.				
h. I rely on a breathing machine to keep me alive.				
i. I need someone to help take care of me all of time.				
j. I can no longer control my bladder.				
k. I can no longer control my bowels.				
l. I live in a nursing home.				
m. I can no longer think clearly—I am confused all the time.				
n. I can no longer recognize family/friends				
o. I can no longer talk and be understood by others.				
p. My situation causes severe emotional burden for my family (such as feeling worried or stressed all the time).				
q. I am a severe financial burden on my family.				
r. I cannot seem to "shake the blues."				
s. Other (write in):				

**Instructions** To help others make sense out of your answers, think about the following questions and be sure to explain your answers to your loved ones and health care providers.

If you checked "worth living, but just barely" for more than one factor, would a combination of these factors make your life "not worth living?" If so, which factors?

If you checked "not worth living," does this mean that you would rather die than be kept alive?

If you checked "can't answer now," what information or people do you need to help you decide?

## Your Beliefs and Values

Initials & Date: \_\_\_\_\_

**Instructions** Circle yes, not sure, or no to indicate whether you agree with each statement. If you do not agree with the "always" statements, this could mean that you agree with these statements some of the time, but not always. You can use the space at the bottom of the page to explain and clarify your beliefs.

### Personal and spiritual beliefs

Many people have special personal or spiritual beliefs that they want respected in decision making about life-sustaining treatments. What are yours?

I believe that it is <u>always</u> wrong to withhold (not start) treatments that could keep me alive.	<b>Yes</b>	<b>Not sure</b>	<b>No</b>
-------------------------------------------------------------------------------------------------------	------------	-----------------	-----------

I believe that it is <u>always</u> wrong to withdraw (stop) treatments that could keep me alive after they've been started.	<b>Yes</b>	<b>Not sure</b>	<b>No</b>
-----------------------------------------------------------------------------------------------------------------------------	------------	-----------------	-----------

I believe it is wrong to withhold (not provide) nutrition and fluids given through tubes, even if I am terminally ill or in a permanent coma.	<b>Yes</b>	<b>Not sure</b>	<b>No</b>
-----------------------------------------------------------------------------------------------------------------------------------------------	------------	-----------------	-----------

I do not wish to receive a blood transfusion or any blood products, such as plasma or red blood cells.	<b>Yes</b>	<b>Not sure</b>	<b>No</b>
--------------------------------------------------------------------------------------------------------	------------	-----------------	-----------

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.	<b>Yes</b>	<b>Not sure</b>	<b>No</b>
------------------------------------------------------------------------------------------------------------------------------------------------------------------	------------	-----------------	-----------

(write in name) \_\_\_\_\_

I believe in other forms of treatment, such as healing through prayer, acupuncture, or herbal remedies. I want the following treatments included in my care:	<b>Yes</b>	<b>Not sure</b>	<b>No</b>
--------------------------------------------------------------------------------------------------------------------------------------------------------------	------------	-----------------	-----------

I believe that controlling pain is very important, even if the pain medications might hasten my death.	<b>Yes</b>	<b>Not sure</b>	<b>No</b>
--------------------------------------------------------------------------------------------------------	------------	-----------------	-----------

I believe that my loved ones should take their own interests into consideration, as well as mine, when making health care decisions on my behalf.	<b>Yes</b>	<b>Not sure</b>	<b>No</b>
---------------------------------------------------------------------------------------------------------------------------------------------------	------------	-----------------	-----------

I believe that it is acceptable to consider the financial burden of treatment on my loved ones when making health care decisions on my behalf.	<b>Yes</b>	<b>Not sure</b>	<b>No</b>
------------------------------------------------------------------------------------------------------------------------------------------------	------------	-----------------	-----------

I believe that my loved ones should follow my directions as closely as possible.	<b>Yes</b>	<b>Not sure</b>	<b>No</b>
----------------------------------------------------------------------------------	------------	-----------------	-----------

Additional beliefs and/or explanations for my beliefs:

\_\_\_\_\_  
\_\_\_\_\_

Initials & Date: \_\_\_\_\_

## Hope for recovery

People have different feelings about hope that influence what health care they want. What are your feelings about hope?

*Imagine that you are very sick and have been told that you will very likely die soon.*

I would want all possible treatments, even though my doctors don't think they will help me, because I would hope for a miracle cure that would prolong my life.

**Yes      Not sure      No**

*Imagine that you have been in a coma for three weeks. The doctors think that the chance that you will ever return to your previous state of health is very small.*

I would want to be kept alive indefinitely because I would still hope for a new medical development that would help me to recover.

**Yes      Not sure      No**

## Weighing pros and cons of treatment for different chances of recovery

People evaluate the pros and cons of medical treatments in very personal ways. This explains why some people choose a treatment and others reject it. A big question is, how much would you be willing to endure if the chance of regaining your current health was high? What if the chance was low? Answer the questions below to carefully evaluate your own willingness to take such risks.

*Imagine that you are seriously ill. The doctors are recommending treatment for your illness, but the treatments have very severe side effects, such as severe pain, nausea, vomiting, or weakness that could last for 2-3 months.*

I would be willing to endure severe side effects if the chance that I would regain my current health was:

high (over 80%)	<b>Yes</b>	<b>Not sure</b>	<b>No</b>
moderate (50%)	<b>Yes</b>	<b>Not sure</b>	<b>No</b>
low (20%)	<b>Yes</b>	<b>Not sure</b>	<b>No</b>
very low (less than 2%)	<b>Yes</b>	<b>Not sure</b>	<b>No</b>

Initials & Date: \_\_\_\_\_

### How would you like to spend your last days?

Many people have strong opinions about what would be important to them at the very end of their lives. For some, they want to express things they would like to have happen. Others want to be sure that certain things they dislike or fear will be avoided. What are some of the things that you would hope for that could make your last weeks, days, or hours the most peaceful?

**Instructions** For each row, check (✓) one answer to express how important these issues would be to you if you were dying.

	Not Important	Moderately Important	Very Important	Extremely Important
a. Avoiding pain and suffering, even if it means that I might not live as long.				
b. Being alert, even if it means I might be in pain.				
c. Being around my family and close friends.				
d. Being able to feel someone touching me.				
e. Having religious or spiritual advisors at my side when I die.				
f. Being able to tell my life story and leave good memories for others.				
g. Reconciling differences and saying "good-bye" to my family and friends.				
h. Being at home when I die.				
i. Being in a hospital when I die.				
j. Being kept alive long enough for my family to get to my bedside to see me before I die, even if I'm unconscious.				

k. What are your biggest hopes about the end of your life?

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l. What are your biggest fears about the end of your life?

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Initials & Date: \_\_\_\_\_

### Other related matters

The topics that have been covered up to this point have related to decisions about your health care in the event you could not speak for yourself. Your decisions about the next topics would go into effect after your death. We include them here because they are related issues that you may want to communicate to others. There is a list of organizations and other resources on page 52 if you need more information about these related matters.

### Organ donation and autopsy

Sometimes after death, organs and tissues can be used to help other people who need them. Family members must give consent to transplant your organs. You can help them make this decision by letting them know how you feel about this. After an autopsy, the body can be shown and buried.

**Instructions** Circle one word to express how you feel.

I want to donate any viable organs/tissues.      **Yes**      **Not sure**      **No**

If yes, have you filled out an organ donor card?

Have you told your family?

I consent to the use of all or part of my body for medical research.      **Yes**      **Not sure**      **No**

If yes, do you have a preference for a research institution?

Have you told your family?

I permit an autopsy.      **Yes**      **Not sure**      **No**

### Burial arrangements

People often leave instructions about what they want done with their bodies after they die. Some want to be buried in a particular place, perhaps in a cemetery with other family. Other people would prefer to be cremated and have their ashes put or scattered in a special place. You can indicate your preferences by answering the questions below.

I would prefer to be: (circle one)      **Buried**      **Cremated**      **No preference**

I would like my remains to be placed: \_\_\_\_\_

Other preferences: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

Initials & Date: \_\_\_\_\_

## Funeral or memorial services

People have different ideas about funerals and memorial services. These services are often very comforting to family and friends as they celebrate and honor the life of their loved one. Services also can make a statement about one's religious faith. Write in below any thoughts about a funeral or memorial service such as where it should be held, songs or readings to be included, where donations should be sent, information for an obituary notice, or other wishes.

This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and extend across the width of the page. There are no margins, text, or other markings on the paper.

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## **More information about health conditions and treatments**

### **What will I learn from this section?**

This section is intended to be a reference that will answer your questions such as,

- What's it like to be in a coma?
- What would happen if you needed CPR?
- Is being on a mechanical ventilator (breathing machine) like being in an iron lung?
- What are the key things to think about when making decisions about life-sustaining treatments?

### **Where can I get answers to other questions?**

If you still have questions after you've read these pages, you can:

- Ask your doctor. Take these pages with you to your next appointment so your doctor can give you more specific information about what these health conditions and treatments might mean for you, given your current health condition.
- Call one of the organizations listed on page 52.

### *Coma*

#### **What is it?**

Coma is a state of unconsciousness that persists for some time. It may be caused by a head injury, a severe stroke, bleeding in the head, or a severe illness. A person who is unconscious shows little or no movement or response to stimulation. It usually looks as though they were asleep. A related and more serious condition is called persistent vegetative state (PVS). A person in PVS is unconscious but sometimes opens his or her eyes and may have unintentional movements such as yawning, and random movements of the head or limbs. PVS usually develops after about a month in a coma.

#### **What's it like?**

People who have been in a coma (and then come out of it) usually say they have no memory of any awareness at all during the coma. These people generally report no memory of pain or discomfort. Those few people who say they were aware of things going on around them or hearing what was being said near them were not in a true coma. Observation of coma patients typically shows no sign that the patient is in any pain or distress. People in coma do not get out of bed, or communicate in any way. They are usually cared for in a

hospital or nursing home because they need to have all of their personal care done for them including being fed through a tube, having their body wastes cleaned up, and being turned every few hours to prevent bed sores.

#### **What's likely to happen?**

Just after a person goes into a coma, it is very hard to predict what will happen. If and when the person comes out of a coma depends on his or her age, what caused it, and his or her overall health. People have very little chance of ever coming out of coma that was caused by illness after about 3 months, or one that was caused by a head injury after about 12 months. There are stages of coma. A person in a lighter stage of coma has a better chance of coming out of it than someone in deeper stages.

#### **What are the key things to think about?**

Would you want to be kept alive after the point in time when your doctors think that you probably won't ever come out of the coma?

Would you want to be kept alive if the doctors felt sure that if you were to come out of the coma, you would have permanent brain damage or other severe limitations?



## ***Dementia***

### **What is it?**

Dementia is a condition in which there is a loss of memory and other mental functions, serious enough to affect interacting with other people. The most common types of dementia are due to Alzheimer's disease, AIDS, and multiple strokes. Other types of dementia can occur as a result of head injury, heavy use of alcohol, or thyroid problems. With the most common forms of dementia, mental functions get worse over time. These include memory, thinking, talking, problem solving, and perception.

### **What's it like?**

Some people in the early stage of Alzheimer's disease may be aware of their forgetfulness, but as the dementia progresses, they will become totally unaware of the forgetfulness and other mental deficits. They will lose the ability to concentrate. Later, there may be mood changes whereby they may lose interest in things around them, or become agitated or violent on occasion even with family members. In still later stages, they become less active, less talkative. In the latest stages, they may no longer recognize close family or friends, lose their sense of day and night, and wander around the house at odd hours.

### **What's likely to happen?**

Most types of dementia are irreversible and will get worse over time. Exceptions include dementia caused by thyroid problems, as well

as memory problems due to depression which are treatable and may be reversible. The speed of deterioration is unpredictable, but severe dementia from Alzheimer's usually occurs within 5-10 years from the first signs of memory loss. In later stages, people with dementia become incontinent, losing control of their bowels and bladder. They often require nursing home care because they need daily help with feeding, dressing, and bathing and this is often more than most families can handle. As they lose interest in eating, complications of malnutrition such as infections and skin ulcers can lead to death.

### **What are the key things to think about?**

If you had severe dementia and then became ill with a reversible illness, such as pneumonia, would you want treatment even though the treatment would not help your memory problems? What if treatment included going to the hospital?

If you were unable to eat enough and were severely demented would you want to receive your nutrition and fluids through a feeding tube placed directly into your stomach?

Some people with dementia seem happy while others seem sad or upset. If you were severely demented, how much should other people pay attention to your mood when making decisions about what is best for you?

# Stroke

### What is it?

Someone who has sustained an injury to a part of the brain, either because of a blockage in the blood vessels, or a burst blood vessel, is said to have had a stroke. Strokes rank third among all causes of death and are a major cause of long-term disability, but not all strokes cause disability. The kind of disability a person develops depends on what part of the brain is damaged and how severely. A stroke is also known as a “cerebrovascular accident,” or a CVA.

### What's it like?

The most common effects of a stroke are: (1) weakness or loss of movement and sensation in an arm, a leg, or both on one side of the body, (2) difficulty speaking, (3) partial loss of sight in one or both eyes, (4) trouble swallowing, and (5) problems understanding what other people are saying. Some people experience changes in their mood or personality. Depression is common among people who have had a stroke, often because of injury to the brain.

### What's likely to happen?

With the most minor of strokes, a person has a loss of feeling or ability to move a part of the body for less than a few days. With moderate strokes, a person may lose the ability to use one arm, need to walk with the assistance of a cane or walker, and have some slurring of speech. With serious strokes, a person might lose the use of one entire side of the body, need assistance to get out of bed and into a chair, or may not be able to speak or understand others at all. With the most severe strokes, a person often loses consciousness and falls into a coma. Most recovery from strokes happens within the first few days up to about 3 months, though modest improvements may continue up to 12 months. After that, whatever disability remains is likely to be permanent.

### What are the key things to think about?

Every stroke is different and so is a person's ability to adapt to losses in function and disability. Many people find that with time and help they can adjust to their new circumstances after a stroke. If you had a stroke, what level of disability do you think you would want to live with? Are there some situations that you would find unacceptable? If so, what are they?

## ***Terminal illness***

### **What is it?**

Every illness that causes death has a terminal stage. That stage is defined as the point when treatments can no longer work to reverse the illness or keep the disease from getting worse. No matter what treatments are given, the person is going to die within a short time. It is very hard to predict exactly how much time a person has to live at this stage, but most doctors expect they will live about six months or less.

### **What's it like?**

During a terminal illness people often lose strength and become confined to bed either in their own home, or if they need more help, in a hospital, nursing home, or hospice (see page 36). Their bodies will begin to shut down. This may or may not be accompanied by pain. Some terminal illnesses, such as the later stages of cancer, can be painful, although medications can control the pain. Appetite usually diminishes. As people get closer to death they will almost certainly think and communicate less clearly.

### **What's likely to happen?**

Near death there are times when people are not able to express their wishes clearly. Some people experience short periods of mental confusion, for example, they drift in

and out of awareness over the course of a day. Many people lapse into a coma just before they die. For example, they may become dehydrated or develop an infection that, if it is not treated, could cause death more quickly than their primary terminal illness. If the treatments for these conditions are successful, they would postpone the moment of death and might prolong any suffering or discomfort associated with the terminal illness.

### **What are the key things to think about?**

If you had a terminal illness, what would be the most important thing for you: relieving suffering or prolonging life?

What would be your goals for treatment of any other problems if you had a terminal illness? Treatment for secondary problems (such as an infection) would not cure the primary terminal illness (such as cancer or heart disease).

# *Kidney Dialysis*

### **What's the problem?**

If your kidneys stop functioning, waste products build up in your bloodstream. As a result, you may feel sick to your stomach, tired, weak, have little appetite and have swelling. In addition, you may have difficulty breathing or thinking clearly.

### **What's kidney dialysis?**

Dialysis is a process in which your blood is circulated outside your body into a machine that removes waste products. A needle is inserted into one of your veins (usually in your arm) and an attached tube carries a steady flow of your blood into the machine. After the blood is cleaned, it is returned to your body through a second tube and needle that is inserted into another part of your vein. You lie in a bed next to the machine during each dialysis session, which usually lasts about four hours. You probably have three sessions a week. If you need long-term dialysis, you have an operation to place a shunt (special blood vessels) in your arm so the needles can be inserted repeatedly over time without collapsing your veins.

### **What happens if I decide not to get dialysis?**

If the waste products in your bloodstream continue to accumulate, you will feel worse and worse. After some time you will go into a coma and then (usually within a week), your heart will stop. How quickly this occurs depends on your overall condition, but can be between a few days to a month. If you go through

this process, you would receive care to keep you as comfortable as possible.

### **What are the good points of getting dialysis?**

Dialysis allows people with kidney disease the chance to lead a near-normal life. Dialysis can relieve some of the symptoms associated with kidney failure. For those patients who are eligible for a kidney transplant, dialysis can keep them alive while they wait for a donor.

### **What are the bad points of getting dialysis?**

Dialysis takes over one of the many functions of your kidneys, so it can't do as good a job as a healthy kidney. Because of this, waste products build up in your body between dialysis sessions, which means that at times, you may not feel very well. You will have to be careful about the amount and types of food you eat. You also will be more prone to infections, bleeding from your stomach or bowel, swelling or bloating, and be easily fatigued.

You will have to spend at least 12 hours a week on a dialysis machine. You may have to travel to a dialysis center for care, which will involve additional time and possibly help from others.

If you have another serious illness besides kidney failure, especially those involving your lungs, liver, or heart, dialysis treatment may be hard to take because of difficulties regulating your body fluids and waste products.

## ***CPR— Cardiopulmonary Resuscitation***

### **What's the problem?**

During a life-threatening illness or a heart attack, your heart may suddenly stop beating and you may stop breathing. Or your heart may beat so irregularly that it no longer effectively pumps blood to your brain. These events mostly occur for people with heart disease, but can also occur without any known cause. Soon after blood stops moving to your brain you will lose consciousness and not be aware of anything going on around you.

### **What's CPR?**

CPR involves vigorous pressing on your chest to keep blood circulating while electrical shock is applied to your chest to “jump start” your heart. Mouth-to-mouth breathing is used to restart your own breathing, or a breathing tube is placed into your windpipe and air is pumped into your lungs to help you breathe. You receive medications through a tube placed in one of your veins. Typically, all this goes on for about 15-30 minutes.

### **What happens if I decide not to get CPR?**

With or without CPR, you will almost immediately lose consciousness. Without CPR, death will follow in about five to ten minutes.

### **What are the good points of getting CPR?**

If you are in relatively good health when you need CPR, it can return you to roughly the same state you were in when your heart stopped.

For people with some types of heart disease, CPR can restore an irregular heart beat. Pain or discomfort is not an issue while you receive CPR because you are not conscious during the process.

### **What are the bad points of getting CPR?**

After CPR, however, you could have a sore chest or broken ribs because of the electrical shocks and vigorous massage. In addition, the chest compressions could result in a collapsed lung, which would require additional treatment. Most people who need CPR need a mechanical ventilator to support their breathing afterwards.

The success rate for CPR depends on many things: your overall health when you need it, where you get it (in the community or in the hospital), your age, and how quickly it starts after your heart stops beating. If you are under age 65, the success rate ranges between 25-40%. If you are over age 65, this rate drops to between 1-4%. CPR is rarely successful if you already have a chronic illness that affects your vital organs, such as your heart, lungs, liver, or kidneys. Less than ten out of 100 hospitalized patients respond to CPR by returning to the state they were in before their heart stopped. Of those who survive, many continue to live, but in a weaker state or with significant brain damage because blood could not get to their brain in time. CPR could keep you from dying, but you might live in a coma or be unable to think clearly.

## ***Feeding Tubes - Artificial delivery of nutrition and fluids***

### **What's the problem?**

You may find yourself unable to swallow food. This could happen after an accident that damages your throat. It could also happen if you are unconscious or have some kinds of brain damage. When this happens you will be unable to take in enough food and water by mouth to keep yourself alive.

### **What's a feeding tube?**

A feeding tube is used to carry liquid nutrition and fluids into your body. One kind of tube goes up your nose, down your throat, and into the stomach. This is called a nasogastric tube. It is about 1/8 of an inch in diameter. Another kind of tube is surgically placed into the wall of your stomach. The operation is quick and safe and you will feel little discomfort. Once the tube is in place it is painless.

### **What happens if I decide not to get a feeding tube?**

If you don't receive any nutrition or fluids you will fall into a state much like a deep sleep. This will take about one to three weeks, during which time, you will be kept comfortable. For example, ice chips on your lips will help keep them moist. Usually, after several days, you will no longer experience thirst or hunger. Also, you will not feel pain as easily as you do now. Within a day or two after you enter this deep sleep, your heart will fail and death will follow within five to ten minutes.

### **What are the good points of getting a feeding tube?**

A feeding tube can provide your nutritional and fluid needs. With adequate nutrition, you will be less likely to get bedsores. A feeding tube is not painful, although the kind that goes down your nose (nasogastric tube) can be uncomfortable. The surgically placed stomach tube is easy to manage without help from others as long as you can take care of yourself. With this kind of tube, you can pour the liquid nutrition into the tube, move about and bathe, all on your own. This tube is placed under your clothes, so other people would not know you have one.

### **What are the bad points of getting a feeding tube?**

Having a tube down your throat will feel somewhat uncomfortable and unpleasant, although not truly painful. You could aspirate liquid (get it into your lungs) which can cause pneumonia. With either tube, you will not be able to taste anything. Receiving fluids might make it harder for you to control urination if you are confined to a bed.

If you are already in the terminal stage of an illness, a feeding tube will likely postpone your death. Tube feeding also makes it possible (in some cases) to keep people alive who are in a coma, have severe strokes, or severe dementia for a long time, even if they might not have wanted it.



## ***Mechanical Ventilators*** ***(Breathing machines)***

### **What's the problem?**

You may not be able to breathe on your own for a number of reasons. Perhaps you have been in an accident that has damaged your airways. You might have a serious lung disease, or maybe you have suffered brain damage. You need a machine to breathe for you, either for the short term (a few hours to a few days) or for the long term (the rest of your life). It may be impossible to tell how long you will need it.

### **What's a mechanical ventilator?**

Mechanical ventilators (also called breathing machines or respirators) completely take over the task of breathing. A tube is placed into your windpipe, either through your mouth or nose or through a small surgical incision at the base of your neck. The tube is about 3/4 of an inch in diameter, about as big as a dime. The tube will make it hard or impossible to talk. Most patients on a mechanical ventilator are in a hospital, usually in an intensive care unit. They are usually not able to get out of bed. In some situations, a portable ventilator allows a patient who is completely paralyzed to get around in a specially-equipped wheelchair.

### **What happens if I decide not to get a mechanical ventilator?**

Without some external breathing assistance, you will die quickly. If you stop breathing, you will die

within five minutes. You could be given medications that will sedate you. These medications help you relax so you will not panic or feel like you are struggling for breath.

### **What are the good points of getting a mechanical ventilator?**

Mechanical ventilation is a painless, although often uncomfortable, way to continue your life. It is often needed for only a short time, for example, just long enough to let your body recover from a serious illness. In some cases, it can relieve the discomfort of feeling breathless. If you need a ventilator for a long time, it can sustain your life indefinitely when you might otherwise die.

### **What are the bad points of getting a mechanical ventilator?**

Even if you are conscious, you will not be able to talk very well or at all. You will likely be confined to bed. You will also be dependent on others to bathe, feed, and dress you and to take care of your bowels and bladder. Nurses will also need to suction your lungs to keep them clear of mucus. It may be hard to tell how long you will need to be on a ventilator. If you have a terminal illness, a mechanical ventilator will only prolong dying.

# ***Hospice and Palliative (Comfort) Care***

## **What's hospice care?**

Hospice is an approach to caring for people with terminal illness. The goal of hospice is to provide comfort care to control pain and other physical symptoms, and deal with the emotional and spiritual needs of dying persons and their families in the last 6 months of life.

Hospice care usually involves a team of professionals, including a nurse, a social worker, a doctor (although not always your personal doctor) and a chaplain or other spiritual advisor. Other health care providers and volunteers, such as physical therapists and chore workers, are called in as needed.

Hospice care can be provided in the home or in special care units in hospitals and nursing homes. The home hospice team usually comes to the house 1-3 times a week, but is available by phone 24 hours a day.

## **What are palliative care and comfort care?**

The terms palliative care and comfort care are both used to mean relieving symptoms and minimizing discomfort. Examples include medications and other treatments to control pain, nausea, fatigue and shortness of breath. They also include nursing care to keep you clean, dry, and comfortable.

Sometimes, curative treatments, such as antibiotics, blood transfusions, chemotherapy, or even surgery, are offered to patients as palliative care because these treatments can make them more comfortable.

Palliative and comfort care should be given to all people experiencing

discomfort. They are not just for people who are in the last months of life or who are getting hospice care.

## **What happens if I decide not to get hospice care?**

Your health care providers will continue to treat new symptoms or infections as they occur. They will treat you either in or out of a hospital, depending on how much care you need. They tend to focus on relieving discomfort due to physical symptoms. They often do not focus on addressing the emotional and spiritual needs of dying people.

## **What are the good points of getting hospice care?**

Hospice care is a holistic approach that focuses on helping dying people make the most out of each day.

Many people seek hospice care so they can die at home. Hospice can support the patient and family to make this happen.

## **What are the bad points of getting hospice care?**

Agreeing to hospice usually means that patients must recognize and accept that their illness cannot be cured and that they will probably die in the next 6 months. Some people view this as a failure because they think it means they are giving up.

Usually, getting hospice care at home means that patients must have family or friends who can provide hands-on care up to 24 hours a day. Therefore, sometimes it's easier for patients, as well as their loved ones, to get their final care in a hospital.



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## **Your specific health care preferences**

### **Why should I fill these out?**

- These forms are very specific about your wishes. You can attach them to your advance directive to provide a detailed picture of your preferences.
- In conditions when you can't speak for yourself, health care providers want to know how you feel about different treatments, especially CPR, mechanical ventilators, and feeding tubes. These forms will make it easier for your family and health care providers to give you the care you want.

### **Why are there 3 parts to each page?**

The 3 parts reinforce each other. Treatment decisions are often based on thoughts about quality of life. For example, if people think that life with severe dementia would be difficult but acceptable, they might want some treatments but not others that would keep them alive.

- Part A lets you express your feelings about the quality of life for each of the different health conditions. This is helpful for your loved ones and caregivers.
- Part B gives a clear message about each treatment. This is very useful to health care providers.
- Part C gives you room to explain your reasons for Parts A & B, such as why you would want some treatments but not others.

### **Why does comfort care have a checkmark (✓)?**

Because no matter what else you decide, your health care providers will always try to give you medications and care to keep you clean and comfortable.

Initials & Date: \_\_\_\_\_

### Current Health

The information on this page could help others make decisions for you if you become unable to speak for yourself. The first part will give others an overall sense of how you view your current health situation.

#### Part A: Feelings about quality of life

*Check the answer that best describes how you feel about your current health.*

My life right now is just fine <input type="checkbox"/>	My life right now is difficult, but acceptable <input type="checkbox"/>	My life right now is worth living, but just barely <input type="checkbox"/>	My life right now is <u>not</u> worth living <input type="checkbox"/>
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#### Part B: Preferences for different life-sustaining treatments

Imagine that you develop a life-threatening illness and couldn't speak for yourself. The doctors feel there is a good chance you would recover to your current health, but you might need one or more of the following treatments.

*Check an answer for each treatment that best reflects what you would want.*

	I would want to receive this treatment	I would rather die naturally and not have this treatment	I don't know/can't answer right now
Antibiotics			
CPR			
Feeding tube: for a short time			
for the rest of my life			
Dialysis: for a short time			
for the rest of my life			
Mechanical ventilator: for a short time			
for the rest of my life			
Comfort care	✓		
Other treatments: (fill in)			

#### Part C: Reasons for my decisions or other comments

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Initials & Date: \_\_\_\_\_

## Permanent Coma

Imagine you are in a permanent coma (see pg. 28 for details). This means you:

- do not think, hear, or see anything
- are not in any pain
- are confined to a bed because you cannot move
- need 24-hour nursing care for bowel and bladder functions and skin care

### Part A: Feelings about quality of life

*Check the answer that best describes how you would feel about being in a coma for the rest of your life.*

Life like this would be difficult, but acceptable <input type="checkbox"/>	Life like this would be worth living, but just barely <input type="checkbox"/>	Life like this would <u>not</u> be worth living <input type="checkbox"/>
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### Part B: Preferences for different life-sustaining treatments

Imagine that while you are in a coma, you develop a life-threatening illness. The doctors feel that no matter what treatment you receive, you will remain in a coma, but the treatment will keep you from dying.

<i>Check an answer for each treatment that best reflects what you would want.</i>	I would want to receive this treatment	I would rather die naturally and not have this treatment	I don't know/can't answer right now
Antibiotics			
CPR			
Feeding tube: for a short time			
for the rest of my life			
Dialysis: for a short time			
for the rest of my life			
Mechanical ventilator: for a short time			
for the rest of my life			
Comfort care	✓		
Other treatments: (fill in)			

### Part C: Reasons for my decisions or other comments

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Initials & Date: \_\_\_\_\_

## Severe Dementia

Imagine you have severe dementia (see pg. 29 for details). This means you:

- cannot think or talk clearly, are confused and no longer recognize family members
- seem uninterested in what's happening around you
- are not in any pain
- are able to walk, but get lost without supervision
- need help with getting dressed, bathing, and bowel and bladder functions

### Part A: Feelings about quality of life

*Check the answer that best describes how you would feel about having severe dementia for the rest of your life.*

Life like this would be difficult, but acceptable <input type="checkbox"/>	Life like this would be worth living, but just barely <input type="checkbox"/>	Life like this would <u>not</u> be worth living <input type="checkbox"/>
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### Part B: Preferences for different life-sustaining treatments

Imagine that while you have this dementia, you develop a life-threatening illness. The doctors feel that no matter what treatment you receive, you will remain demented, but the treatment will keep you from dying.

*Check an answer for each treatment that best reflects what you would want.*

	I would want to receive this treatment	I would rather die naturally and not have this treatment	I don't know/can't answer right now
Antibiotics			
CPR			
Feeding tube: for a short time			
for the rest of my life			
Dialysis: for a short time			
for the rest of my life			
Mechanical ventilator: for a short time			
for the rest of my life			
Comfort care	✓		
Other treatments: (fill in)			

### Part C: Reasons for my decisions or other comments

Would your answers be different if you seemed happy most of the time? **Yes** **No**

Would your answers be different if you seemed unhappy most of the time? **Yes** **No**

How?

Initials & Date: \_\_\_\_\_

## Severe Stroke

Imagine you have had a severe stroke (see pg. 30 for details). This means you:

- are able to think, but your ability to understand what is said to you and communicate with others is severely limited
- have aches and pains that make you uncomfortable most of the time
- are able to walk with a walker, but most of the time you get around in a wheelchair
- need help with getting dressed, bathing, and bowel and bladder functions

### Part A: Feelings about quality of life

*Check the answer that best describes how you would feel about a severe stroke for the rest of your life.*

Life like this would be difficult, but acceptable <input type="checkbox"/>	Life like this would be worth living, but just barely <input type="checkbox"/>	Life like this would <u>not</u> be worth living <input type="checkbox"/>
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### Part B: Preferences for different life-sustaining treatments

Imagine that in addition to the stroke, you develop a life-threatening illness. The doctors feel that no matter what treatment you receive, you will still have your stroke-related problems, but the treatment will keep you from dying.

<i>Check an answer for each treatment that best reflects what you would want.</i>	I would want to receive this treatment	I would rather die naturally and not have this treatment	I don't know/can't answer right now
Antibiotics			
CPR			
Feeding tube: for a short time			
for the rest of my life			
Dialysis: for a short time			
for the rest of my life			
Mechanical ventilator: for a short time			
for the rest of my life			
Comfort care	✓		
Other treatments: (fill in)			

### Part C: Reasons for my decisions or other comments

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Initials & Date: \_\_\_\_\_

## Terminal Illness

Imagine you are expected to die within the next two months (see pg. 31 for details about terminal illness). This means you:

- have days when you drift in and out of awareness
- have a lot of discomfort that requires medication
- are in bed most of the time due to weakness
- need help with getting dressed, bathing, and bowel and bladder functions

### Part A: Feelings about quality of life

*Check the answer that best describes how you would feel about having a terminal illness.*

Life like this would be difficult, but acceptable <input type="checkbox"/>	Life like this would be worth living, but just barely <input type="checkbox"/>	Life like this would <u>not</u> be worth living <input type="checkbox"/>
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### Part B: Preferences for different life-sustaining treatments

Imagine that in addition to the terminal illness, you develop a life-threatening illness. The doctors feel that no matter what treatment you receive, you will get weaker and die in about 2 months, but the treatment will keep you from dying immediately.

*Check an answer for each treatment that best reflects what you would want.*

	I would want to receive this treatment	I would rather die naturally and not have this treatment	I don't know/can't answer right now
Antibiotics			
CPR			
Feeding tube: for a short time			
for the rest of my life			
Dialysis: for a short time			
for the rest of my life			
Mechanical ventilator: for a short time			
for the rest of my life			
Comfort care	✓		
Hospice			
Other treatments: (fill in)			

### Part C: Reasons for my decisions or other comments

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Initials & Date: \_\_\_\_\_

## A future situation of concern when I might not be able to express my wishes

My doctor has told me that given my particular circumstances, I could end up like (write in a description of possible future situations):

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### Part A: Feelings about quality of life

*Check the answer that best describes how you would feel about this situation.*

Life like this would be difficult, but acceptable <input type="checkbox"/>	Life like this would be worth living, but just barely <input type="checkbox"/>	Life like this would <u>not</u> be worth living <input type="checkbox"/>
-------------------------------------------------------------------------------	-----------------------------------------------------------------------------------	-----------------------------------------------------------------------------

### Part B: Preferences for different life-sustaining treatments

Imagine that in addition to the situation described above, you develop a life-threatening illness and are unable to communicate. The doctors feel that no matter what treatments you receive, you will still have the problems described above, but the treatments will keep you from dying.

*Check an answer for each treatment that best reflects what you would want.*

	I would want to receive this treatment	I would rather die naturally and not have this treatment	I don't know/can't answer right now
Antibiotics			
CPR			
Feeding tube: for a short time			
for the rest of my life			
Dialysis: for a short time			
for the rest of my life			
Mechanical ventilator: for a short time			
for the rest of my life			
Comfort care	✓		
Other treatments: (fill in)			

### Part C: Reasons for my decisions or other comments

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## **How to talk about your wishes**

### **How can this section help me?**

- Talking about end-of-life issues is often difficult, both for you and your family. We've included some sample scripts to give you specific ideas about how to start and get family and care providers to listen to you.
- This section also gives you tips on how to make sure that your family and health care providers not only hear you, but understand you.
- There is a list of nine issues to discuss, so you'll be sure to cover all the important points.
- The last page has questions and answers about legal and ethical issues to consider as well.



### Talking about your wishes.

Perhaps the single most important step in advance care planning is talking about your wishes with whomever might be called upon to speak for you. Whether or not you complete a formal advance directive, you still need to express your preferences clearly to your loved ones and health care providers.

Talking with your loved ones and health care providers can also help you think about what you want. Often they will ask you questions or tell you things that will make you think about your wishes in another way. The more thoroughly and clearly you communicate, the easier it will be for everyone to do the right thing.

#### Starting the discussion

There is no "right" way to start this conversation. Nor is there a "right" time. The best thing to do is make a time and get started. But what if loved ones resist? 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 started:

- **Relate a story from this book.**

If there was a story from the first part of this book that got your attention, it may also get the attention of the person you want to talk to. Share this story with them to 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 stories of friends or relatives who experienced an illness and faced a difficult situation. You could start the conversation saying,

*"Do you remember what happened to so-and-so and what his family went through? I don't want you to have to go through that with me. That's why I want to talk about this now, while we can."*

- **Be firm and straightforward.** If someone puts you off out of their own discomfort, you could say,

*"I know this makes you feel uncomfortable, but I need you to bear with me and 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."*

- **Use a letter, tape, or video**

**recording.** It may be easier for people to hear what you have to say initially 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 preferences. Afterwards, they may be more ready to sit down and talk with you.

### **Asking someone to be your spokesperson**

When you ask someone to be your spokesperson, you are asking them to assume a big responsibility that you both want to be comfortable with. To ease into the conversation, you might ask questions like:

*“Would you be willing to represent my views about medical decisions if I can’t speak for myself?”*

*“Can you make decisions for me that are based on my values, preferences, and wishes—even if they’re not like yours?”*

You do not want this person to agree to be your spokesperson if they really have strong misgivings about it. So be sure to tell them that you will not be offended or hurt if they feel they cannot do this for you.

If the person agrees to be your spokesperson, you can reassure them that you are not expecting them to be “superhuman” or all-knowing. Give them explicit permission to make decisions for you, especially for those situations that you haven’t discussed or couldn’t predict.

### **Who else should you talk to?**

Think about the people who play an important part in your life. Then try to imagine a time when you are either seriously ill or injured and unable to communicate. Who would you want to be around at such a time? These are the people you should make a point of sharing

your feelings with now. They might include:

- Your spokesperson
- Family
- Health care providers
- Friends
- Other caregivers
- Clergy

You do not need to speak to everyone at the same time. However, it can be helpful to talk to your family as a group so that they all hear what you have to say in the same way.

### **What if you don’t have close family or friends?**

Your best option is to write down your wishes, either in an advance directive or personalized statement, or both. You could also make a tape or video recording of your wishes. Then be sure to share it with your health care providers.

### Nine important issues to discuss

We recommend that you talk about the following issues. Discussing them will help avoid confusion, conflict, and hurt feelings between loved ones and care providers.

#### 1. Your Choice of a

**Spokesperson**—Let your loved ones and care providers know who you have chosen to be your spokesperson—and why. This is especially important if your spokesperson is not a member of the family. You might say something like this:

*“I’ve asked so-and-so to be my spokesperson in case I need medical care but can’t speak for myself. My choice is not a reflection of my relationship with you. But after careful thought, I feel that he/she is the right person to handle this responsibility for these reasons...”*

**2. Your Beliefs**—Tell those close to you what it is that makes life worth living, as well as what would make it unbearable—and why. If you have fears about being a burden, explore these feelings with those who will care for you. Family members often view caring for loved ones as an honor—not a burden. Use the exercises in this workbook to help you talk about these issues.

**3. Health Conditions**—Share how you feel about being kept alive in conditions that could leave you unable to speak for yourself.

**4. Life-sustaining Treatments**—Share how you’d feel about different medical treatments, including hospice, and under what circumstances you would or would not want to receive them.

**5. Your Vision Of A Good Death**—If you hope to die in a certain way—whether it’s at home, in your sleep, with family by your side, or free of pain—tell people.

**6. Organ Donation**—If you’d like others to benefit from your healthy organs after your death, make sure you family understands this because they *must* give their permission.

**7. Funeral Arrangements**—Share your thoughts about what you want to be done with your remains. If you have ideas about what you would like for a memorial service or how you’d like an obituary to read, talk about that too.

**8. Documentation Of Your Wishes**—If you’ve decided to complete an advance directive or write a personalized statement, tell people where they can find this information in the *future*.

#### 9. Helping others use your personalized directive—

Instructional directives and personal statements can be understood either as specific instructions, or as general guidelines. You can help others interpret your written wishes by including something like this in your document:

*“I would like the statements in my personalized directive followed to the letter.”*

*“I would like the statements in my personalized directive to be used as a general guide.”*

*“I want those statements that I’ve marked with a star (\*) followed to the letter because I feel very strongly about them. Use the rest of my statements as a general guide.”*

### Talking to your health care providers

Here are a few reasons why it is important to talk to your health care providers about advance care planning:

- They need to know that you've documented your wishes in an advance directive or personalized statement. Without this knowledge, your health care providers could make treatment decisions that may not agree with your wishes.
- You want to be sure that they will interpret your wishes or your advance directive in the way you intend. If they believe your words mean one thing, while your spokesperson or family members interpret it differently, you'll probably get treatment until they can resolve their differences.
- Your health care providers can answer questions you may have about different health conditions, treatments, and your prognosis.

### Make a special appointment

To make sure you've got their attention, make a special appointment with your health care provider to talk about this. Health care providers are people too—some are uncomfortable talking about end-of-life issues, or have other things on their mind. You don't want to be in a hurry when you have this conversation.

If your health care provider wants to just file your advance directive in your chart without discussing it, don't let that happen! Make sure they know *why* you feel the way you do. This will make it easier for them to understand and follow your wishes.

### What to say

To help you organize your thoughts and cover all the important issues, bring a copy of your advance directive and any exercises you completed from this workbook, particularly those on pages 20-24 and 38-43. Also during this appointment, you may want to ask some or all of these questions:

*"Given my current health, am I at risk of facing a situation when I might not be able to communicate?"*

*"Is there anything about my current health that would compromise the likelihood of success of different treatments?"*

*"Can I count on you to respect my wishes and contact my spokesperson if I'm unable to speak for myself?"*

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

### Reviewing your wishes

With all the advances in medicine and health care, it's a good idea to review your wishes from time to time. Values and preferences for health care often change with age or when there are changes in your health condition. When and how often you review your wishes depends on your circumstances.

#### Changes in your family situation

If your spokesperson moves, you get a divorce, or a family member dies, you may need to rethink who will speak for you.

#### When you are healthy

When you're healthy, a periodic review prepares you and your family for emergency situations, such as a car accident or a sudden illness. Here are some ideas about good times to schedule these reviews.

- **Just before an annual check-up with your health care provider.**

You'll refresh your memory about what you said last year, and then be ready to talk about new questions or concerns at your appointment.

- **Special anniversary dates.**

Some people pick dates such as a birthday or the first day of spring. By picking the same date every year, it gets on your "to do" list and becomes a part of your routine.

- **Holidays or other family gatherings.** Others like to do this during these times so they can take advantage of having everyone together in the same place. This makes it easier to share their views with everyone all at once.

#### When your health changes

Another important time to think about your wishes is if your health condition changes, especially if it takes a turn for the worse. Here are some things to think about in these circumstances.

- **Adjusting to new limitations.**

People often think that if they had physical or mental limitations their life would be terrible. But some people adjust to limitations and disability and find that life still has a lot to offer them. After you've given yourself some time to get used to your new situation, take another look at the exercise on page 21 to see if your thoughts have changed about what makes life worth living.

- **Concerns about being a burden.**

It's normal for people with new limitations to feel like they are a burden because they need more help from others. But be sure to ask your family members what it means to them to be a burden before you "spare" them. You may be taking away their chance to return the gift of the love and care that you've given them.

#### When you are dying

After people learn they are dying, they often rethink their priorities. Their attention often shifts to making the most of the time they have left. The exercise on page 24 can help you focus on what's important at this time.



## Legal and ethical issues of advance care planning

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

**A:** Generally speaking, you need to sign your advance directive and have it witnessed. There are instructions with the forms in the back pocket that cover the steps you need to take to make your directive a legal document.

**Q:** *Will my advance directive be legal in all 50 states?*

**A:** The laws vary from state to state, but most states will recognize the *intent* of an advance directive. If you have a home in more than one state, check with your health care provider or a lawyer in each state—one form might work for all places.

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

**A:** Yes, but if they disagree with the preferences you indicate in your advance directive, they should refer your care to another provider. In a minority of cases, providers have “overruled” patient directives because they felt that the circumstances at the time did not match what was written.

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

**A:** Most health care facilities have an Ethics Committee who can help resolve disagreements between family members or family members and providers. Talking with your caregivers ahead of time can help avoid future conflicts.

**Q:** *Is withdrawing treatment considered suicide?*

**A:** Most people would say “no.” Withdrawing or stopping a treatment after it has been started, is one way that patients can exercise their right to refuse treatment especially if the treatment does not seem to be achieving the desired goal. However, some religions believe otherwise. You may want to check with your religious advisor to be sure.

**Q:** *What is the difference between withholding and withdrawing treatment?*

**A:** From an ethical and legal standpoint, there is no difference between these two: both are ways to stop unwanted or ineffective treatments. However, not all religions agree with this view—again, you should check with your clergy. Also, some people feel it is harder to withdraw treatment once it is started than to withhold it. But having the option to withdraw treatments means that doctors can give treatments a try, then stop them if they aren't working.

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

**A:** No. Assisted suicide is currently illegal. However, even if it becomes legal, the person making the request would have to be competent and able to change their mind at the time of the suicide. Advance directives only go into effect when you are no longer competent to make decisions.