

Family Conversations

Booklet 1 of 2

*How to Talk With Your Family and Friends
About Future Health Care Decisions*

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How to Talk With Your Family and Friends About Future Health Care Decisions

Getting Started

Family members and close friends all too often find themselves faced with the need to make health care decisions for their loved ones. These decisions are required because people become unable to make decisions for themselves. As long as you can speak for yourself, you always are in-charge of your healthcare decisions. Unfortunately, serious illness often causes confusion, pain, weakness, and sometimes unconsciousness (coma). If you are unable to speak for yourself, someone will make decisions for you.

Ask yourself:

Are you willing to leave to chance the person chosen to make decisions for you?

Will this person make the decisions that you wanted made?

Will this person know that you are counting on him or her to make decisions?

There is a way to make sure that your wishes are followed by those people who you trust to follow them. It starts with conversations with your loved ones about your future health care decisions.

The purpose of this booklet is to get you started in having these conversations and to help you put your choices in writing. Spoken words get changed from person to person. Written words do not change and people can go back and read them again.

Whether you are young, middle aged or elderly, in good health, or poor health, talking with your family is a good idea. Your family members, significant others, and close friends can be spared the agony and uncertainty of whether or not they are making the right decision on your behalf.

How to Use This Booklet

This booklet will help you to:

- **clarify** how you feel
- **know** who you want to make decisions on your behalf if you are unable
- **decide** what is important to you in your future health care decisions

- **guide** you through family conversations
- **answer** some important questions about your health care decisions

A companion booklet called **Writing Your Choices Down** will help you to:

- **understand** the laws about health care decisions in West Virginia
- **write down** your choices on the West Virginia forms

Following—you will find four stories that show real life situations. The names and details have been made up, but the issues are very real. Read them carefully and then go through the four steps on page 4 (Step 1. Think about the stories; Step 2. Prepare for your conversations; Step 3. Talk about the stories; Step 4. Answer questions about your health care choices.

These stories show just how important it is to talk with your and families, significant others, and close friends.

CASE 1

Brenda Smith

Brenda is a 23 year old woman who has just moved out of her parents' house and is working at a nursing home in the next county. She is living with several good friends from school. One night on the way home from a family gathering, Brenda is in a serious car accident. She is taken by helicopter to the University Hospital where she lies unconscious in the Intensive Care Unit. The doctors believe that she will never wake up and they turn to Brenda's family for a decision about the use of the life-sustaining breathing machine. You are Brenda's parent. What decision would you make? What decision would Brenda make for herself?

CASE 2

Peter Worthington

Peter is a 65 year old man who is retiring from his job as the principal of the local high school. He has had a couple heart attacks in the recent past and would like to slow down a bit and enjoy his grandchildren. Peter is divorced and remarried with two grown children from the first marriage and three more grown children from his present marriage. Peter and Marge, his wife, are planning an extended trip to visit grandchildren. A week before they are scheduled to leave, Peter has another major heart attack and is in the cardiac care unit of a local hospital. Peter remains unstable weeks after his heart surgery and seriously ill. The doctors turn to Peter's family for a decision about cardiopulmonary resuscitation(CPR) when his heart fails again. What would you say as a member of Peter's family?

CASE 3

Sarah Moore

Sarah is an 78 year old widow who lives alone on her family farm. Her husband died ten years ago and all of her family have moved away. The closest relative is a niece who lives in a neighboring state. Sarah has lived on this farm all of her life and it means the world to her. Sarah's health is failing and her neighbors are concerned that she can no longer live on the farm alone. She has been getting by with the help of her church and her neighbors. One day Sarah is discovered unconscious by a friend. At the local hospital she is found to have had a stroke. She is beginning to recover, but rehabilitation will be slow. She is very agitated and uncomfortable. The doctors turn to Sarah's family and friends for a decision about nursing home placement. What would you say?

CASE 4

Jim Boone

Jim is a 75 year old man with dementia who was diagnosed with Alzheimer's disease about five years ago. He is living at home with help from his wife, Katie, his two daughters who live near by, and a local home care agency. Jim rarely speaks, is confined to a chair most of the day, and is no longer able to go to the bathroom on his own. Jim had stopped feeding himself a few weeks ago and is being fed by his wife and daughters. During the past week, he has begun to clamp his mouth shut, pushing food away, and spitting out food. Over the weekend, even coaxing with Jim's favorite foods didn't work. The doctor turned to the family for a decision about putting in a feeding tube. What decision would Jim have made for himself if he was able?

Having conversations about future health care decisions would have been very helpful for the patients and families in these stories. You can prevent unnecessary suffering by those you care about and who care for you by having conversations with them. Don't end up like this. Have conversations while you are able. Do it for yourself. Do it for those you love.

Here's how you and your family can have conversations about future health care decisions.

Step 1 THINK about the stories. Put yourself in the patient's shoes. What would you want? Who would you want to make decisions for you? Put yourself in the families' shoes? How would you make this decision? What would you want for your loved one? What would you like to know about their wishes?

- Step 2 PREPARE for your family/friend conversations.**
Decide who you want at the meeting
Let them know why you have asked them to talk with you
Choose an agreed upon place and time to have the conversation
Make sure you have enough time
Turn off the TV
- Step 3 TALK about the stories with your families and friends. You can even read them aloud. Use the questions provided below.**
- Step 4 WRITE down the answers to the questions about your health care choices.**

Questions to Consider and Talk About With Your Family and Friends

Write down your answers as you go through these questions.

- **Who would you want to make decisions for you if you are not able to make decisions for yourself?**

Things to consider:

Who knows you best? _____
 Who knows your wishes best? _____
 Who do you trust? _____
 Who is going to be around? _____
 Who is going to be willing and able to make your health care decisions for you?

 Who is going to be able to make sure that the doctors carry out your wishes?

 Is that person going to be afraid to choose something that you didn't want?
 Yes ___ No ___ Don't Know ___
 Is that person going to be afraid of making health care decisions?
 Yes ___ No ___ Don't Know ___
 Will they have concerns about what other family members may say?
 Yes ___ No ___ Don't Know ___
 Will they have concerns that the doctor might be wrong?
 Yes ___ No ___ Don't Know ___
 How will you reassure them? _____

Who did you choose?

Name: _____

Address: _____

Phone: _____

Who would you want as a second person if the first person is not around or able to make decisions?

Name: _____

Address: _____

Phone: _____

• **What is most important to you in your health care decisions?**

Things to consider: Is it important for you.....

To live as long as possible? Yes ___ No ___ Don't Know ___

To stay in your home? Yes ___ No ___ Don't Know ___

To be able to return to do the things that you did before?
Yes ___ No ___ Don't Know ___

To be able to communicate with family and friends?
Yes ___ No ___ Don't Know ___

To avoid pain and suffering? Yes ___ No ___ Don't Know ___

To avoid being connected to machines?
Yes ___ No ___ Don't Know ___

Sometimes it is not possible to do all the things that are important to us. Sometimes our values are in conflict. Think about what things above are the most important.

For example: You may want to die at home, but sometimes you can only get a certain treatment at the hospital. Which is more important – to stay at home or get a treatment?

Pain medication may cause you to be sleepy. What is more important - to be free of pain or to be awake and aware of people around you?

You may be able to live longer if you are on a breathing machine or a dialysis machine that cleans your blood. Being on machines may cause further pain and/or suffering. What is more important - to live longer or to be free of pain and suffering? _____

Being on machines may allow doctors to be more sure about whether your treatment will work. Being on machines may cause further pain and/or suffering. What is more important - being certain that you will not get better or being free of pain and suffering? _____

- **When would you not want doctors to use lifesaving treatment for you?
(check all that apply)**

When I am likely to die in a short time (see Case 2, Peter Worthington) _____
 When I am unconscious and unaware of my surroundings (see Case 1, Brenda Smith) _____
 When I am in a lot of pain (see Case 3, Sarah Moore) _____
 When I cannot recognize friends and family members because I have dementia (see
 Case 4, Jim Boone) _____

- **Are there any specific medical treatments that you would wish to avoid?
(check all that apply)**

Cardiopulmonary Resuscitation (CPR) - attempts to restart my heart when it has stopped – (see
 Case 2, Peter Worthington) _____
 Breathing Machines – (see Case 1, Brenda Smith) _____
 Food and Water through tubes in my arm or in my stomach – (see Case 4, Jim Boone) _____
 Dialysis - machines to clean my blood _____
 Surgery _____

OTHER RESOURCES

The West Virginia Center for End-of-Life Care
www.wvendoflife.org 1-877-209-8086 (toll-free)
 The West Virginia Center for Health Ethics and Law
www.wvethics.org
 The West Virginia University Center on Aging
<http://www.hsc.wvu.edu/coa> 1-888-WV-AGING (toll-free)