

Family Conversations

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

Booklet 1

Developed by:
West Virginia University Center on Aging
West Virginia Center for End-of-Life Care

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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 in some situations people become unable to make decisions for themselves. As long as you can speak for yourself, you are always in charge of your health care decisions. Unfortunately, serious illness often causes confusion, pain, weakness, and sometimes unconsciousness (coma). In you are unable to speak for yourself, someone will need to 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?
- Will this person know that you are counting on him or her to make decisions?

There is a way to make sure that those people who you trust follow your wishes. 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, *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

The following four stories are based on 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.

These stories demonstrate just how important it is to talk with your 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 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 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 several 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 see the 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 is 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 a 78-year-old widow who lives alone on her family farm. Her husband died ten years ago and all of her family has 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 health 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 for those you care about and who care for you by discussing your wishes with them. Don't end up like this. Have conversations while you are able. Do it for yourself. Do it for those you love.

How To Talk With Your Family About Your Health Care Decisions

Here are some suggestions to help you discuss future health care decisions with your family.

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 your family's 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 and friend conversations.

- Decide whom you want at the meeting.
- Let them know why you have asked them to talk with you.
- Choose an agreed upon time and place to have the conversation.
- Make sure you have enough time.
- Eliminate distractions such as television, radio, and young children.

Step 3

TALK about the stories with your family 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? _____

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 I don't know

Is that person going to be afraid of making health care decisions?

Yes No I don't know

Will they have concerns about what other family members will say?

Yes No I don't know

Will they have concerns that the doctor might be wrong?

Yes No I 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 about your health care decisions?

It is important for you...

To live as long as possible?

Yes No I don't know

To stay in your home?

Yes No I don't know

To be able to return to do the things that you did before?

Yes No I don't know

To be able to communicate with family and friends?

Yes No I don't know

To avoid pain and suffering?

Yes No I don't know

To avoid being connected to machines?

Yes No I 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 to you. 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
- Get a treatment

Pain medication may cause you to be sleepy.

Which is more important:

- To be free of pain
- To be awake and aware of the 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.

Which is more important:

- To live longer
- To be free of pain and suffering

Being on machines may allow doctors to be more certain about whether your treatment will work. They may cause further pain and/or suffering.

Which is more important:

- Being certain that you will not get better
- To be free of pain and suffering

Life Saving Treatment Options

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 my friends and family members because I have dementia (see Case 4, Jim Boone)

Are there specific medical treatments that you wish to avoid? (Check all that apply)

- Cardiopulmonary Resuscitation (CPR) - attempts to restart the 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

West Virginia Caregivers
www.wvcaregivers.org

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
www.hsc.wvu.edu/linkage/index.html
1-888-WV-AGING (toll-free)

For additional copies and information on caregiving contact:

West Virginia University Center on Aging, PO Box 9125
Morgantown, WV 26506-9125
304-293-2968
www.wvcaregivers.org

For additional copies and more information contact:

West Virginia Center for End-of-Life Care
1195 Health Sciences North, PO Box 9022
Morgantown, WV 26506-9022
1-877-2009-8086
www.wvendoflife.org

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