My Health-My Decision

A class to help people, who can make decisions, be more involved in their health care decisions

This booklet belongs to:

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Ardmore Enterprises
Melwood
Montgomery County Dept. of Health and Human Services
Resource Connections of Prince George’s County
Service Coordination: A division of The Arc of Frederick County
The Southern MD Regional Office of the Developmental Disabilities Administration
The Maryland Developmental Disabilities Council

March 2005
Introduction:

We put this training together to make sure that you know that you have the power to make your own health care decisions, now, and in the future. It is your health and your decision.

Health care is a very personal thing but sometimes you may be told what to do rather than be allowed to have a say in each step that it takes to keep you healthy and comfortable along the way.

You have the power and the right to make choices about everything that affects you. You also have the responsibility to balance what is good for you with what you may not like.

For example, you may not like salad or vegetables but you eat them because you know that they are good for you. You may not like going to the dentist but you know that you should because you want healthy teeth. All adults make these decisions.
Sometimes people who care about you can help to make decisions easier. But the bottom line is that you have control over the details and the final say in all of your health care decisions.

So let’s talk about how you can be in better control over your health care decisions now and how you can think about planning way ahead for the times when you may be really sick and need more help.
We want to teach you four things today:

1. How to make decisions.

2. How to have more power over your health care decisions.

3. How to pick people you trust to help.

4. How to plan way ahead.
Part 1: How to make decisions

You make lots of decisions every day.

✦ What time do I get up?
✦ What do I have for breakfast?
✦ What do I wear today?
✦ What do I watch on TV?

You should also be making a lot of decisions about your health.

✦ When should I go to my doctor?
✦ Should I exercise today?
✦ How often should I brush my teeth?
✦ When should I take my medication?
✦ Who can take me to my doctor appointment?

*If you are not making these basic choices then you should talk about this with someone you trust or at your next planning meeting.*
The most important thing to know is that you are the one to be making the decisions. *There should be no surprises for you about your health care.*

You should know about everything that is to happen. Staff should not be making decisions without you and your family should not be making decisions without you. In some cases you may want or need their help and we will talk more about this later.

*If people are making decisions without you and you are not happy about this then you should talk to someone you trust, to your Resource Coordinator, or to people at your next planning meeting.*

You need to know that with all decisions there are always choices to make. Let’s look at an example of a health care decision to find out what the choices are.
In this example you have the health care decision of to go to the dentist every 6 months or to not go to the dentist every 6 months. So you have a few choices. In order to figure out your choices you need to ask some questions.

Should I go to the dentist every 6 months?

Yes or No?

What may happen if I do not go to the dentist every 6 months?

What may happen if I do go to the dentist?

What other information do I need?
Who could help me if I am scared or need someone to talk to, to help me, or to go with me?

Can I just wait?

Waiting can be good. You may feel more in control or you may get more information but waiting too long may cause other problems.

When you need to make an important choice about your health care you can use this map on the next page to help you to make your choice or get more information to help you make the best choice for you.

Let’s fill it out together.
Should I go to the dentist every 6 months?

What may happen if I go?
- I will have clean healthy teeth
- I will feel better
- It may hurt
- I feel out of control
- I feel scared
- Costs money
- Going every 6 months may keep my teeth from hurting
- It may avoid bigger problems

What may happen if I do NOT go?
- It will still hurt
- People will hassle me
- I may lose my teeth
- I may have bad breath
- I may get bigger problems

Can my dentist give me something to help me relax?

Who can help?
- What else do I need to know?

Can I talk to my dentist ahead of time?

Yes

No
So in this example you see that every decision has a lot of things to think about. You see that there are a lot of questions to ask.

The most important thing to think about is that there are choices with every decision. You need to find out what those choices are so you feel like you have all the information you need to make a good decision.

People are there to help you so it is important to remember to ask people for their help.

But remember that the final decision is yours.
Part 2: You have the power in your health care decisions

Let’s now talk about what needs to happen to make sure that you have the power in your health care decisions.

It is important to say that you are an adult and responsible for yourself. Just because you may need help to make some decisions does not mean that you have less rights than other people. You have a say in every part of your health care.
So what needs to be there to make sure that you are in charge?

1. Doctors talk to you respectfully.
2. Doctors and staff talk to you.
3. Paperwork is explained to you before you sign the papers.
4. People respect your privacy (confidentiality).
5. People respect your body and let you know if something may hurt.
6. You are given time to ask questions.
7. You are given time to make decisions.
8. You are given time to talk to other people.
9. More than one choice is explained to you.
10. You help to schedule doctor visits.
11. Your comfort is always considered.
12. You select a different way to make it easier if something is hard, like having someone else take you, taking a pill to help you relax, or going to a new doctor.

You have the right to ask for all of these things. It is your right as a person. If anything on this list is not happening for you, you can talk to your staff, your family, or your doctor to make sure that it is looked into. You can also talk about it at your yearly planning meeting.

Show them this list.
Part 3
How to pick people you trust to help you?

We all need help from time to time. Sometimes asking other people for their advice is good. It helps us to think of things from a different point of view. Plus it is nice to know that people care about us.

We want to help you choose the best person to help you with health care decisions.

We would like for you to think about the people who you know and trust the most. Some people you trust with secrets. Some people you trust to help you.

It is usually best to choose someone who is either a family member or a trusted friend. It is your decision, as you are the best judge of who you trust the most.

There are people who you trust who can help you to make decisions. There are people who you trust who can make decisions for you.
Sometimes there are limits on who can make decisions for you. A paid staff usually can’t make medical decisions for you. Neither can a friend who may not understand or could not help you to understand.

On a piece of paper write the name of the person who you trust the most who you think could help you make good medical decisions.

Now figure out where this person fits on the chart.

If you are the center of the circle then who is closest to you?

People who love you most would be closer to you. People who you see often would be closer to you.
Now write the person you have chosen on the line below:

___________________________________________________________
Write the name of the person that you selected here

Please share this training booklet with this person after the training and let them know that you picked them.

This could start you both talking about whether they can help you with health care choices.
There may be certain medical decisions that may be too hard for you to make or you are too sick to make them. You can allow someone else to make these decisions for you. This is called “appointing a health care agent”.

In some cases you can have this person just make one decision for you (like whether or not to have a surgery) or in another case you can turn over all the decision making to them (like all the choices that come with a certain treatment). It is your choice.

Appointing a health care agent is another choice that you have. So think about who this could be and talk about it at your yearly planning meeting. It will most likely be the person that you chose to write down on the last page. Make sure that who you choose is written down so everyone will know.
Part 4
Plan Way Ahead

Planning way ahead is hard for a lot of people. We may not want to think about if we get really sick or if we have to go into a hospital.

This next section is a little hard to talk about so we will be extra kind as we go on. We will understand if you do not want to talk about it. You can just sit and listen.

While it is hard it is also important to plan ahead. We do not want our loved ones guessing at what it is that we may want. So it is helpful to talk about this with people who care about you and get it written down so when the time comes people will know what you want when you may not be able to tell them.
These are questions that we want you to think about and try to answer. This may be the first time that you have ever thought about some of this stuff so we ask that you think about it, make a best guess and then maybe talk it over with people you trust.

Again, if you feel uncomfortable answering some of these questions you do not have to, we ask that you just listen and then maybe think about them in the future.

Who would you like to make medical decisions for you if you are too sick to do it for yourself?

Do you have a hospital that you prefer to go to?

Who would you want to be called first if you had to go into the hospital?

Who else would you want to know that you were in the hospital and very sick?

Would you want people visiting you if you are real sick?
Are there things that you would want with you in the hospital? Like a special pillow, blanket, pajamas, warm socks?

Would you want extra medication to make sure that you do not feel pain even though it may make you sleep more than usual?

Would you want to be hooked up to life support machines if there was no hope of you ever waking up again?

Would you want people from your church or synagogue to be praying for you or visiting you?
If you had to go into a nursing home until you got better what would you want people to know or do?

Have you ever thought about being so sick that you may not get better?

It is scary to think about. But even in this situation you still want to be as involved in the decisions or decide who should be helping you.

Have you ever thought about dying?
Have you ever thought about whether you want to be buried or cremated?

Would you have a place that you would want to be buried or a special place for your ashes?
Have you ever thought about what kind of memorial service that you would want? Special music, favorite sayings, certain church or synagogue, certain funeral home?

As we said before these are important things to think about and share with others. You do not want people guessing about the things that are important to you and getting them wrong.

Try and answer these questions and share this information with other people who know you, care about you and support you. Make sure that this information is shared with those people and kept up to date.
You can get help to fill out a legal paper which makes sure that your choices are carried out. Or you can fill out a “Five Wishes” booklet.

**Five Wishes** asks a lot of the same questions that we talked about, so it should be easy to fill out after this training. The Five Wishes booklet, after it is signed, is a legal document for people to follow your wishes in the way that you say. More and more people are using this Five Wishes booklet to share their wishes. Ask your agency for a copy.
Final Thoughts

Do you have any questions before we end?

Thank you very much for coming today and answering some very tough questions.

The agency that supports you wants to make sure that they are doing a good job in helping you to make the best decisions about your health now and in the future.

They wanted to make sure that you got information on how best to make your own health care choices.

We ask that you share this information and booklet with people who support you and care about you. Also talk about this at your yearly planning meeting.

Our hope is that you live a happy, healthy life surrounded by people who know you and care deeply about you.