



# My Health, My Decisions: Supported Decision-Making and Health Care

What do I do if I need help with my health care?

What if it's hard to talk to my doctors or ask them questions?

What happens if I have trouble understanding my treatment or taking my medication?

People with disabilities and their families ask these questions every day.

Everyone should take care of their health. Going to doctors, getting treatment, taking medicine, eating right, being safe, and exercising are all important parts of being healthy.

So, what should you do if you need help with health care? Of course, everyone is different. What you do will depend on what you want to do, what you're good at, and what you need help doing.

This brochure will tell you about things you can try, that can help you make health decisions and be the center of your medical care.





## Taking the Lead: *Self-Determination*

Do you like being in charge of your life?  
Do you want to be the one who “calls the shots” and decides who you spend time with, where you go, and what you do?

When you make decisions and take actions to shape your life, it’s called self-determination. When you’re self-determined you do things instead of having things done to you, you make choices instead of someone else telling you what to do. When you go to the doctor, you take the lead, talk about

how you feel, listen to the doctor's recommendations, and decide what kind of medical care you'll get.

It feels good to be self-determined, doesn't it? It's also good for you. For years, studies have shown that when people with disabilities are more self-determined, they have better lives: they're more likely to be healthy, employed, independent, safe, and an active part of their communities.<sup>1</sup>

Isn't that also what parents want? Parents want their children to be as happy, healthy, safe, and independent as possible. That's why, for people with disabilities and their families, self-determination is the key to living the best, healthiest life possible.

# Getting Help:

## *Making Self-Determination Work*

Being self-determined doesn't mean you never need help. Everyone needs help, every day.

People may:

- Ask their friends for advice about relationships.
- Talk to their co-workers about job issues.
- Go to professionals for help saving and spending money.

Always remember, getting help doesn't mean you're not self-determined. It means you're smart because you're getting what you need to be self-determined.

Getting help is important when you're taking care of your health. When you go to the doctor, you may not be feeling well, you might be nervous, or the doctor may use words that are hard to understand. It's a good idea to have someone with you, to help you and the doctor talk and work with each other. That way, you'll be able to understand your options and choose the one that's best for you.





In the next few pages,  
you will read about  
some ways  
you can get help making  
health care decisions.



# Someone Else Making Decisions for You:

## *Guardianship*

Guardianship is a legal process where you go to court and a Judge decides whether you can make decisions for yourself. If the Judge decides that you can't, he or she will choose a "guardian" to make some or all decisions for you.

Many times, people with disabilities and their families are told that guardianship is their only option. Sometimes, that's true. A lot of the time, it isn't.

If you can't make decisions for yourself, even with help, guardianship may be right for you. But, your guardian should still encourage and support you to make choices and express yourself.

If your guardian makes health care decisions for you, your guardian and doctor should listen to you and respect your opinions.

They should make sure you have a chance to:

- Talk about how you feel.
- Tell the doctor if you're worried about something.
- Ask questions about your health.
- Ask questions about what the doctor says you should do, or about medicine the doctor says you should take.
- Say whether you want a treatment or to take a medicine.

That way, you'll have as much self-determination as possible.



## Making Your Own Decisions with Help: *Supported Decision-Making*

Another way is to make your own health and life decisions with help from people you trust.

That's called **Supported Decision-Making**.

People use Supported Decision-Making every day. They work with friends, family members, and professionals who give them advice and information or just help them think about their options. It's simple, really: they support you and you decide.

### **That's Supported Decision-Making.**

Like we said, health care decisions can be hard. You and your doctor must understand each other:

- The doctor must understand how you're feeling or what you think is wrong.
- You must understand what the doctor thinks you should do.
- You must understand your options and think about them.
- You must make a decision about what to do and the doctor has to understand your decision.

Supported Decision-Making can help you manage your health, work with your doctors, and make health care decisions.



People you trust can help you:

- Explain how you're feeling to the doctor.
- Understand and answer any questions the doctor asks you.
- Understand what the doctor says about your condition and what the doctor says you should do to take care of yourself.
- Think of questions to ask the doctor and make sure the doctor understands your questions.
- Think about your options and what you want to do.
- Tell the doctor your decisions and discuss them with the doctor.<sup>2</sup>





## Supported Decision Making: *How Can I Make it Work for Me?*

Even though everyone needs help sometimes, not everyone needs the same type of help in the same ways at the same times. By finding and using the help that works best for you, you'll be able to use Supported Decision-Making to make your own health and life decisions. That way, you can be self-determined and live your best, healthiest life.

Here are some things you can do to help you use Supported Decision-Making.

## THINK, TALK, AND LISTEN

The first thing you should do is think about where and when you want to use Supported Decision-Making. Remember, this is about you and your health, not anyone else. So, think about times when you got help taking care of your health or when you wish you had help. Then think about what you have to do to manage your health care and if you could do that better if you have someone to help you.

Talk to people in your life who you trust and respect. Ask them when they think you could use help or how they could help you. If they've helped you before, talk about those times and if they might be able to help you that way now.

You can also use online tools and guides. One is called "When Do I Want Support?" and is available at

<https://aclu.org/other/when-do-i-want-support>

It can help you think of health and other areas where you may want to use Supported Decision-Making. You can also use it when you're talking to people you know, so you can ask their opinion about things you do well or need help doing.



## IDENTIFY OPPORTUNITIES

Once you know where and when you'd like to use Supported Decision-Making, think about the types of help you'd like to use. You can start by thinking about the help you've used before or that you use now.

*Has someone ever helped you with your health or gone to the doctor with you? If so, who was it and how did they help?*

*Are there things you do now when you must make a tough choice? If so, what are they?*

If something worked well before, you might want to try it when you're making health decisions or managing your health care.

Also, talk with people you trust. Discuss the ways you think you'd like to be helped or ask them for advice. Together, you may come up with some ideas you can try.

You may want to use the "Supported Decision-Making Brainstorming Guide," at <http://bit.ly/sdmbrainstorming>. It can help you explore ways you use Supported Decision-Making now, how you'd like to use it in the future, and who may be able to help.

## FIND AND WORK WITH YOUR SUPPORTERS

Next, work with people you trust to make sure you have the help you need and want so you can use Supported Decision-Making. You can work with friends, family members, and professionals in the programs you use. Talk with them about the ways you want help and when.

Remember, there are many ways people can help you with your health. You can work with different people, at different times, to help you do different things.

You may want:

- A friend to go to appointments with you, to help you talk with the doctor.
- Your parents to help you manage your medication, so you understand what you need to take and when.
- A case manager to help you look for specialists or new treatments.
- A therapist or other professional to help you come up with a plan to manage your health care.

The key is to talk with the people you want to help you, and set up a plan for how they'll do that.

The “Setting the Wheels in Motion” guide, at <http://bit.ly/sdmwheels>, can help you figure out the type of support you want, when you want it, and who you want to help you. The guide was designed to help parents work with their children with disabilities, but you can also use it work with the people in your life.

## PUT IT IN WRITING

Finally, we suggest that you create a Supported Decision-Making Agreement or plan describing the help you want, when you want it, and who you want to help you. That way, you can give the plan to your doctors so they know who will be helping you and when. You can also share the plan with your family and friends, so they can work together to give you the help you want.

Also, a written Supported Decision-Making Agreement shows that you use Supported Decision-Making to manage your health care and life. That’s important because Missouri law says that Judges must consider whether people use Supported Decision-Making before ordering them into guardianship.<sup>4</sup>

Therefore, a Supported Decision-Making Agreement may protect you if someone tries to put you in a guardianship.

You don't have to use a specific form when you write a Supported Decision-Making Agreement. You can create an Agreement that works best for you. There are model forms you can review and adapt at: <http://supporteddecisionmaking.org/node/390>. You may also work with advocates or attorneys to help you write your own form.

**But, always remember, it's your health and your decision – so choose the help that works best for you, the people that work best with you, and the plan that's best for you!**

## References

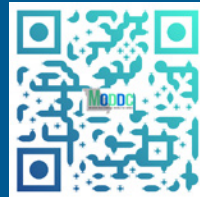
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4. Missouri Code, Chapter 475.075



## We Can Help!

Whether you're just starting to think about how you'll manage your health or you already know what you want to do, we can help! We can answer your questions or connect you with people and organizations that may be able to work with you.

Feel free to contact us at:  
**(800) 500-7878**  
**[moddcouncil.org](http://moddcouncil.org)**



## OUR NETWORK PARTNERS

### **Missouri Protection and Advocacy Services**

(800) 392-8667  
[moadvocacy.org](http://moadvocacy.org)

### **UMKC Institute for Human Development, UCEDD**

(816) 235-1770  
[ihd.umkc.edu](http://ihd.umkc.edu)

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