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SUPPORTED DECISION MAKING AND YOUR HEALTH



How can I take care of my health? Do I need medication? What should I say to my doctor? What happens if my doctors don't understand me or I don't understand them?

People with disabilities ask these questions every day.

We all need to take care of our health. But no one does it alone. We all have people in our lives who help us take care of ourselves!

This brochure will tell you how you can take care of your health with help from people you trust. That's called Supported Decision Making.



Taking the Lead: Self-Determination

Do you like being in charge? Do you want to decide who you spend time with, where to go, what to do, and how to take care of yourself? We all do!

When you make decisions and are in control of your life, it's called self-determination. When you're self-determined you make choices about your life instead of someone else telling you what to do. So, when you go to the doctor, you talk with the doctor and then you decide what to do.

It's good to be self-determined and it's good for you! Studies show that when people with disabilities are more self-determined, they have better lives: they're more likely to be healthy, independent, and safe¹. Self-determination is the key to living your best, healthiest life!



Getting Help: Making Self-Determination Work

Being self-determined doesn't mean you never need help. Everyone needs help sometimes! People we trust give us information, advice, and assistance every day. That helps us do what we need to do to live our best lives.

Always remember: getting help doesn't mean you're not self-determined. Getting help is smart because it helps you be self-determined!

It's especially important to get help when you go to the doctor. You may not be feeling well or you might be nervous. It might be hard to tell the doctor what's wrong or to understand what the doctor is telling you.

That's why it's good to have someone with you to make sure that you and the doctor understand each other. That way, when you have to make a decision about your health, you know you'll be making the best one for you!

Here are some ways you can get help making health decisions.



Someone Else Makes the Decision: Guardianship and Conservatorship

If a Judge decides that you can't make decisions, the Judge will choose a guardian or conservator to make decisions for you. That person will then decide what's best for your health.

If you really can't make decisions, guardianship and conservatorship may be good for you. But, your guardian or conservator should still help you make as many choices as you can and make sure you have a chance to:

- **Talk about how you feel**
- **Ask questions**
- **Learn what you need to do be healthy**
- **Say what you think you should do or what medicine you should take**



Getting Help to Make Your Own Decisions: Supported Decision Making

Another way is to make your own decisions with help from people you trust. That's called Supported Decision Making or SDM for short².

Isn't that how we all make decisions? When you have to make a tough choice and don't know what to do, or just want to "talk it out," what do you do?

You get help. We all do. You may ask a friend for advice or a family member what they think or a professional for information. They help you think about the issues and your options, discuss the "pros and cons," and figure out what you could do. Then you can decide what's best for you.

When you do that, you're using SDM. People you trust give you support, so you can decide. That's it!

Health care decisions can be hard to make. You have to make sure the doctor knows how you're feeling and you understand what the doctor thinks you should do. If you do that, then you'll be in the best position to make the best decision for you.

This is a great time to use SDM! People you trust can help you:

- **Explain to the doctor how you're feeling**
- **Answer the doctor's questions**
- **Understand what the doctor says you should do to take care of yourself**
- **Ask the doctor questions and understand their answers**
- **Think about your options and figure out what you want to do**
- **Talk to the doctor about your decision³**

Using Supported Decision Making for Your Health and in Your Life

Like we said, everyone uses SDM! But, we all use it in different ways, at different times, to help us make different decisions. So, you should use SDM in ways that work best for you!

Here are some questions to help you think about ways to use SDM to take care of your health and lead your best life⁴.

1 When do you want to use SDM?

First, think about think about a time you want (or wished) to have someone help you understand what a doctor or medical report said. Remember, SDM is about you and your health and life. So, you should first think about the times when you wanted someone to help you take care of yourself or make a decision about your health. You may also want to think about times in your life when it would have been good to have someone there to help you.

It's a good idea to talk about this with people you trust. Ask them when they think you could use help or how they could help you.

There are free tools that can help you do this. The *Missouri Stoplight Tool*⁵ can help you think about life areas, like taking care of your health, where you may want help making decisions.

2 How do you want to be Supported?

Next, think about how you want people to help you. Start by thinking about when people have helped you before. If someone gave you good advice, how did they do it? If something worked well, you might want to try it again to help you make a decision about your health.

The **Supported Decision Making Brainstorming Guide** can help you think of ways you used SDM before and how you may want to use it now.

3 Who can Help?

Next, think about who can help you. Talk to your friends, family members, and professionals. Tell them about when and how you want help and ask if they'll help you when you need to make decisions about your health and in your life.

Remember, there are many different ways to get help and many different times when you might want help. You may want:

- **A friend to go to the doctor with you to help you talk with the doctor.**
You can let the doctor know that the friend is there to help you understand the information so you can make good health decisions.
- **Your family to help you remember to take your medication.**
- **Your family and friends to help you pick the best doctor for you.**
- **A doctor to help you make a plan to take care of yourself.**

Talk to as many people as you can!

4 Make a Plan!

Next, make a plan that says:

- **When you want help,**
- **What kind of help you want,**
- **Who you want to help you.**

“I want my friend to help me make health decisions by going to the doctor with me”

This could be as simple as saying, “I want my friend to help me make health decisions by going to the doctor with me,” or “I want my mom to help me with my health by reminding me to refill my medicine every month.”

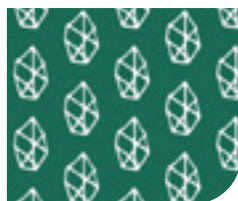
The **Setting the Wheels in Motion Guide**⁶ can help. It was designed to help parents, but you can also use it work with people in your life.

We think it's a good idea to write down your plan. That's called a Supported Decision Making Agreement. You don't have to do that, but we think it's helpful.

If you write down your plan, you can share it with trusted friends, family members, and people and professionals in your life so they'll know that you use SDM, how you use it, when you want to use it, and who is helping you use it.

You don't have to use a special form to write a Supported Decision Making Agreement. You can write one that works best for you. There are model forms you can use or you can work with advocates or attorneys to help you write your own form.

Always remember, it's your health, your life, and your decisions. So, choose the helpers and kind of help that work best for you.





We Can Help!

While some people may need guardians or conservators, we think the National Guardianship Association's position makes sense:

You Should at Least Try SDM.

Wherever you are on your SDM journey, whether you're just gathering information or you're ready to write a plan, we can answer your questions or connect you with people and organizations that may be able to help. Feel free to contact us at: Info@ctsilc.org or visit ctsilc.org

References

This brochure was adapted, with permission, from material published by the Missouri Developmental Disabilities Council.
www.moddc.org

- ¹ e.g. Wehmeyer, M.L., & Schwartz, M, (1997). Self-determination and positive adult outcomes: A follow-up study of youth with mental retardation or learning disabilities. *Exceptional Children*, 63(2), 245-255; Wehmeyer, M. L., & Palmer, S. B. (2003). Adult outcomes for students with cognitive disabilities three-years after high school: The impact of self-determination. *Education & Training in Developmental Disabilities*, 38(2), 131-144; Khemka, I., Hickson, L., & Reynolds, G. (2005). Evaluation of a decision-making curriculum designed to empower women with mental retardation to resist abuse. *American Journal on Mental Retardation*, 110(3), 193-204.
- ² Blanck, P. & Martinis, J. (2015). "The right to make choices": The national resource center for SDM. *Inclusion* 3(1), 24-33.
- ³ e.g. Martinis, J. & Blanck, P. (2019). *Supported Decision Making: From Justice for Jenny to Justice for All. A Theory to Practice Guide*. Virginia: Something Else Solutions Press.
- ⁴ Martinis, J. (2019).
- ⁵ <https://moguardianship.com/>
- ⁶ https://supporteddecisionmaking.org/resource_library/supported-decision-making-teams-setting-the-wheels-in-motion/

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