



# Supported Decision-Making and Your Health

PEATC's Transition to Adulthood Series



## **Taking Care, Taking the Lead:** *Supported Decision-Making and Your Health*

What if I need help with my health? What if it's hard to talk to my doctors or ask them questions? What if I have trouble taking care of myself or taking my medication?

People with disabilities 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 your health? This brochure will tell you about ways you can take the lead in making health decisions and directing your health 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?

*Everyone does.* When you make decisions and direct 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 to the doctor, and decide what to do.

It feels good to be self-determined, doesn’t it? It’s also 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 safe.<sup>1</sup>

Isn’t that what *everyone* wants? That’s why self-determination is the key to living your best life.

# 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 their job.
- Go to professionals for help with their health and 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, the doctor may use words that are hard to understand, or you may think the doctor doesn't understand you. So, it's a good idea to have someone with you, to help you and the doctor understand each other. That way, you'll be able to think about your options and choose the one that's best for you.

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



## Someone Else Deciding for You: *Guardianship*

If a Judge decides that you can't make decisions for yourself, the Judge will choose a *guardian* to make some or all decisions for you.

If you really can't make decisions, even with help, guardianship may be right for you. But, your guardian should still encourage you to make choices and express yourself. If you have a guardian, your doctor should still respect you and make sure you have a chance to:

- Talk about how you feel.
- Ask questions about your health.
- Ask questions about what you should do, or what medicine you should take.

That way, you'll be as self-determined as possible.



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

Another way is to make your own 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 or help them think about their choices. Then they make the choice that's best for them. It's simple, really: people support you and you decide what to do. *That's* Supported Decision-Making.

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

- The doctor has to understand how you're feeling.

- You have to understand what the doctor thinks you should do.
- You have to understand your options and think about them.
- You have to make a decision about what to do and the doctor has to understand your decision.

Supported Decision-Making can help you do all those things. 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 health.
- Understand what the doctor says you should do to take care of yourself.
- Think of questions to ask the doctor.
- 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, we all need different *kinds* of help in different ways at different times. The key is to find the help that works best for you. That way, you'll be able to use Supported Decision-Making to make your own health and life decisions.

Here are some things you can do to help you use Supported Decision-Making.<sup>3</sup>

### **THINK ABOUT WHEN YOU WANT TO USE SUPPORTED DECISION-MAKING**

The first thing you should do is think about *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 someone to help you.

It might help to talk to people in your life who you trust. Ask them when they think you could use help.

You can also use on-line tools. One is called “When Do I Want Support?” and is available at: <https://peatc.org/wp-content/uploads/2022/02/Supported-Decision-Making-Brainstorming-A-PEATC-ACLU-Resource-Document.pdf>.

It can help you think of health and other areas where you may want to use Supported Decision-Making.

### **THINK ABOUT HOW YOU WANT TO BE SUPPORTED**

Next, think about *how* you want to be helped. You can start by thinking about the help you’ve used before. Has someone 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 have to make a tough choice? If so, what are they? If something worked well before, you might want to try it again.

You may want to use the “Supported Decision-Making Brainstorming Guide,” at <https://peatc.org/wp-content/uploads/2022/02/When-Do-I-Need-Support-A-Resource-Document.pdf>. It can help you think about ways you used Supported Decision-Making before and how you might like to use it now.



## **THINK ABOUT WHO CAN HELP**

Next, think about *who* can help you when you need it. You might want to talk to friends, family members, and professionals in the programs you use. Talk with them about the ways you want help and if they'll help you with your health care.

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 with your medication, so you understand what to take and when.

- A case manager to help you look for providers or treatments.
- A therapist or other professional to help you come up with a plan to take care of yourself.

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://supporteddecisionmaking.org/sites/default/files/Supported-Decision-Making-Teams-Setting-the-Wheels-in-Motion.pdf>, can help. The guide was designed to help parents, but you can also use it work with the people in your life.

### **WRITE IT DOWN**

Finally, we recommend that you write a Supported Decision-Making Agreement that says when you want help, how you want to be helped, and who will help you. 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.

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 at: <http://supporteddecisionmaking.org/node/390>.

You can also work with someone to help you write your own Agreement.

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!

## **We Can Help!**

Wherever you are on your Supported Decision-Making journey, we can answer your questions or connect you with people and organizations that may be able to help. Feel free to contact us at:

### **PARENT EDUCATIONAL ADVOCACY TRAINING CENTER**

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# References

- 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 e.g. Dinerstein, R. (2012). Implementing legal capacity under article 12 of the UN convention on the rights of persons with disabilities: The difficult road from guardianship to supported decision-making. *Human Rights Brief*, 19, 8.
- 3 Martinis, J. (2019). Making it happen: Strategies for supported decision-making. *Impact* 32(1), 45.



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