



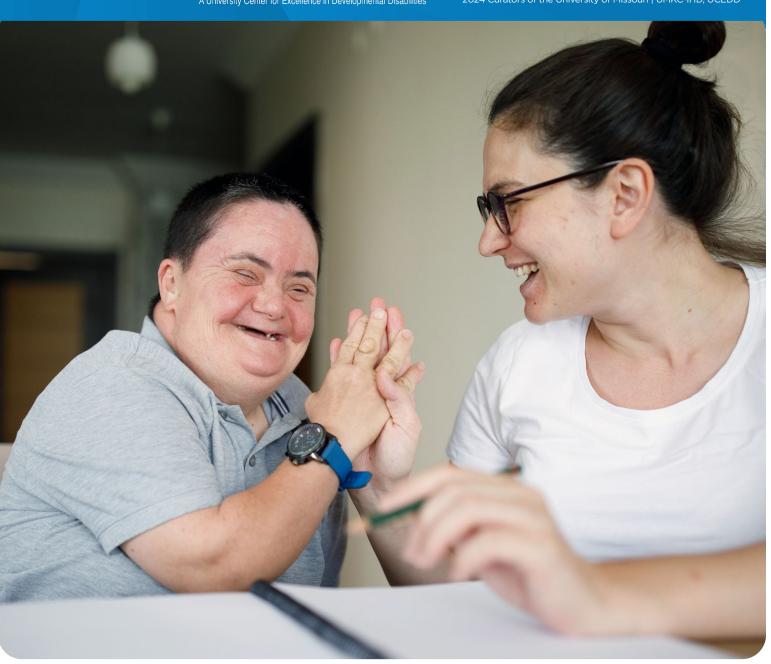
Moving to Adult Health Care:

UNDERSTANDING YOUR LEGAL RIGHTS



www.lifecoursenexus.com

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INTRODUCTION

What Is This and Who Is This For?

Growing up means there are a lot of changes that are going to happen. One of those changes is your health care. The process of moving to adult care is called health care transition. Transition means a change from one thing to another. It does not happen all at once. You are considered transition age if you are somewhere between the ages of 12 and 26.

This guide is part of a set of toolkits that are made for you.

The guides and other tools will give you lots of information and resources to help you during this time of transition. The toolkits are made to help you learn and get ready for moving to adult health care and living a healthy adult life.

This guide is part of the toolkit Moving to Adult Health Care: Understanding Your Legal Rights in Health Care Settings.

To find the other toolkits, please visit movingtoadulthealthcare.org/toolkits/

Made for people with disabilities and their supporters by experts in the field of health care transition, developed in partnership with people who have lived disability experience.

Toolkit Series

- 1. Understanding Health Care Transition
- 2. Knowing About Your Health Care
- 3. Leading Day-to-Day Health Care Routines
- 4. Understanding Your Legal Rights in Health Care Settings
- 5. Leading Your Health Care Visits and Interactions
- 6. Planning for Moving to Adult Health Care

Each toolkit has:

- Information you need to know about moving to adult health care
- Some important words and people to know
- Helpful tips for people who are supporting you
- Resources and supports
- EZ-Readers and videos to help you understand important ideas.





Scan the QR Code with your mobile device to visit the Toolkit Series website.



INTRODUCTION

Learn, Talk, Do.

As you work through this guide you will learn about moving to adult health care and what that means. You will have chances to talk about what you learned with your supporter. You will then have ways to take action on what you learned.



Learn.

You and your supporter will learn about moving to adult health care and resources for additional information.



Talk

Stopping points will be provided for you and your supporter to talk about what you just learned. Supporters will be given additional instructions and discussion ideas in the "supporter" box at these stopping points.



Do

Tools will be provided that can help you apply what you learned. Instructions and examples of how to use the tools can be seen in the guide. You can print and complete the tools at lifecoursenexus.com/health-care-transition.

For Supporters

A supporter is someone who is on your side. A supporter can help you with reading and understanding the information in this guide. You can talk to a supporter and ask them questions about moving to adult health care and what it means for you. They can help you think about and start doing things to get ready for taking charge of health care in your adult life. When you see "For Supporters" with this stamp shown to the right, it means that part is for your supporter to help them help you.



In This Toolkit

In the first three toolkits in the Moving to Adult Health Care series, you learned about what it means to transition from pediatric to adult health care, understanding your own health care and disabilities, different kinds of doctors and health care workers, and everyday things you do for your health as an adult.

In this toolkit, **Moving to Adult Health Care: Understanding Your Legal Rights**, you will learn about your health care rights and laws. You will learn about adult decision-making and how you can get the help you may need with making health care decisions.



Why Learn About This?



Knowing about your rights and how to advocate for them is key to being healthy and living your best life. There are laws that protect your rights specific to health care. These laws help make sure you are treated fairly and can get the health care you need. It is also important to know about your rights to make decisions about your life and how you can be supported in making health care decisions.

Rights



What are Rights?

Rights are rules about how everyone should be treated. A right says what a person is allowed to do or should have. A right is something you have that should not be taken away. People who have a disability have the right to be treated the same as anyone else.

Human Rights

Human rights are the basic rights and freedoms every person has. You have these rights because you are a human being. Examples include being treated fairly and equally, treated with respect, and being safe. You have the right to be treated just like everybody else, no matter who you are and how you live your life.

Legal Rights

Laws are rules that we all must follow. Some rights are put into laws to protect you. These are called **legal rights.** That means someone can get in trouble if they take away or get in the way of you having those rights. Some examples include freedom of speech, the right to vote, and the right to public education.

Important Rights

Discuss with a supporter, family member or friend what rights, human or legal, are most important to you.



ADA and Different Kinds of Reasonable Accomodations

The Americans with Disabilities Act (ADA) is a law that protects you from being treated differently because of your disability. The ADA says reasonable accommodations can be available when going to the doctor or a health care worker. A reasonable accommodation means to make changes to help you have access to and use health care.



Physical Accommodations

Making changes or adjustments so you can get into and out of a building, room, or office. It can also be something to help you get around once you are inside. Examples of physical accommodations include:

- Ramps
- Automatic or hands-free door openers
- Accessible parking, close to the entrance
- Wider doors, curb cuts
- Larger bathroom stalls with grab bars
- Signage in braille



Right to Information in Different Ways

You may need to get information in a different way to help you understand things about your health care. This is called an alternate format. Getting information in alternate formats can help you know things and make decisions about an illness, treatment, and options. It is your job to let your health care workers know what format(s) you need. Alternate or different formats may include:

- Large print materials
- American Sign Language (ASL)
- Braille
- Plain language materials
- Photos or picture formats
- Video or audio recordings

List of Accommodations

Make a list of accommodations you may need. Write down what support you will need to get access to health care and understand health care information. Talk with your supporter if you need ideas or help with making your list. Some questions to think about:

- What is the best way for you to get health information?
- What format is most useful for you?
- Are there physical accommodations you need to get health care?



Mealth Care Rights

- You have the right to get the health care services you need.
- You have the right to not be discriminated against in getting those services. That means you should not be treated differently or denied services because you have a disability.

HIPAA



What is HIPAA?

HIPAA is the federal law that protects your health information. HIPAA is short for the Health Insurance Portability and Accountability Act.

The HIPAA Privacy Rule:

- Protects the privacy of a person's health information.
- Sets limits on how health information can be shared or used.
- Applies to health care providers, health plans and exchange of information between providers and insurance companies.

Right to Privacy



Privacy and Confidentially

You have the right to privacy and confidentiality. That means your doctor *cannot:*

- Tell anyone else what you talk about with them or what happens at your visits.
- Give anyone your health care information unless you know about it and say it is okay.

This includes your parents or family.

Doctor's offices will often use the words "privacy" and "confidentiality" to explain their policies about keeping your information.

Your right to privacy means you can see the doctor by yourself if you choose. That means that your parent or family member cannot be in the room for exams or when talking to the doctor unless you say it is okay.



Right to Privacy (Continued)



Sharing Health Care Information

You must sign a form to give the okay for your doctor to share your health information. Health information that is shared may include things like blood test results or x-rays. People you might want to share your health information with include:

- Someone you trust, like a parent or family member.
- Another doctor or health care worker.

Release Form

Your doctor will ask you to sign a release form before sharing information. You might also be asked if it is okay to text or email you or to leave a message when calling. Signing a release form is a choice; you never have to sign a release form if you do not want to.

There are a few exceptions to this law about privacy and confidentiality. If you tell your doctor that you are planning to hurt yourself or planning to hurt someone else, then the law says the doctor must tell someone and get you help.

Sharing Your Health Information

Think about who, if anyone, you want your doctor to share your health information with. Ask yourself:

- Who do I trust with my health information?
- Do I want help from a family member, friend, or someone else?
- Will this person respect my privacy?
- Is there anyone I do not want to share my health information with?



Right to Health Records and Information

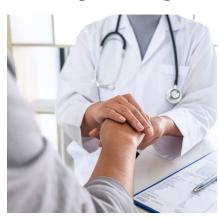


You have the right to ask for and get a copy of your medical and health care records. You might want a copy to:

- Keep in your own records or care notebook.
- Use it to show other doctors the treatments and medications you have tried in the past.

Some doctors may charge a fee to make copies. You can choose how to ask for your records, but using an email or a letter is best. You may also be able to access your information through your health care provider's patient portal.

Building Trusting Relationships with Health Care Workers



Kindness and Respect

You have the right to be treated with kindness and respect. You have the right to be listened to and understood. This means:

- Your thoughts and beliefs should be valued.
- Your concerns should be taken seriously.

If your doctor or health care worker does not treat you with respect or you don't like them, think about finding another doctor. You deserve to be treated with respect in all health care settings.

Feeling Respected

Discuss with a supporter what things a doctor or health care worker can do to make you feel respected. Some examples include listening carefully when you speak, asking for your input, and giving you time to ask questions.



Building Trusting Relationships with Health Care Workers (continued)



Asking Questions and Getting Answers

You have the right to ask questions and have them answered. Your doctor is getting paid to work for you. Speak up if you don't understand something. The doctor is there to meet your needs and answer your questions. This may include asking questions about things like:

- Medications, treatments, or tests.
- Side effects and risks of different treatment options.
- What to expect if you do not choose treatment.

It is okay to ask the doctor to slow down or explain something further. That is their job. You can ask as many questions as you need about your health until you understand what you should know to make decisions about your well-being.

Rights During an Exam



You have the right to ask your doctor or health care worker to explain what they are doing when examining or touching you. When the doctor comes into the exam room, you can say you want to talk before they start the exam. Use this time to ask questions or talk about your concerns. It can be hard to talk about your questions or concerns while they are doing the exam.

Ask your doctor to:

- Tell you what they are going to do to your body before they start the exam.
- Explain what is happening during the exam.

It is your body, and you have the right to have your questions about the exam answered, and you have the right to say "no" to an exam if you do not agree that it will be helpful. You have the right to ask others in the room besides your doctor to leave the room at any time. This could be people like residents, researchers, or medical students.



Right to Another Opinion or to Refuse Treatment

You may decide that you want to talk to another doctor to get a different opinion on the health care issue you are facing. You have the right to decide not to follow the doctor's advice. You can decide whether to say "yes" or "no" to medical treatments. Even if it could save your life, you still have the choice to say no. You are the one who must live with the decisions related to your health care.

Health Care Accommodations



You have the right to ask for extra time on visits or bring your service animal. You also have the right to bring someone with you to visits. It is helpful to have someone with you to provide support during visits. They can help you:

- Focus the conversation with the doctor or health care worker
- Take notes about what happens during the visit
- Remember what the doctor says

Advocating Your Rights



You may have to ask that your access needs be met. If you need an accommodation for regular health care visits, request it from your health care provider or their office.

For accommodations and communication during emergency situations, carry a note or use a medical ID that has the most important accommodations listed on it.

Accessible Health Care

Figuring out how to make health care accessible in a way that works well for everyone requires having a conversation with your health care provider or their office staff. To be prepared, discuss with a supporter what health care accommodations you might need.



KNOWING ABOUT DECISION-MAKING

Position Property Property



It is important to know your rights and how to advocate for them. In some cases, your rights may be limited. If you have a guardian, that person may make decisions for you about your medical care. **Guardianship** is when a court decides you cannot make your own decisions. The court gives someone else (a guardian) the legal right to make decisions for you. A guardian can make decisions about:

- Where you live.
- Who your friends are.
- · How to manage your money.
- · Your health care.



You may not be the final decision maker about your health care, even if you disagree with your guardian. However, a guardian should always ask you about what you would choose and make decisions based on your preferences whenever possible. A guardian can help you learn:

- Skills to make your own health care decisions.
- About making decisions so you may not need a guardian in the future.

You still have the right to be safe, be treated with respect, and ask for reasonable accommodations even if you have a guardian.

Supported Decision-Making (SDM)

You can get support and help with making decisions without having a guardian. One way to get support is by using supported decision-making (SDM). SDM means you make your own decisions with help from others.

With SDM, you choose who you want to help you with decisions. SDM means asking your family, friends, or other people you trust for advice and help with making decisions. Those people are called supporters. You can have several supporters if you choose. Supporters can help you:

- Understand issues and choices
- Ask questions
- Receive explanations in understandable language and accessible formats
- Communicate your own decisions to others

Important Reminder: With SDM, you make the final decisions.



KNOWING ABOUT DECISION-MAKING

Other Decision-Making Options



You can give someone you trust **power of attorney** to act on your behalf. That means they can make health care and other decisions for you when you aren't able. There are many kinds of powers of attorney. For example, your power of attorney might allow others to make decisions:

- · Right away, or
- Only if you get sick, or
- For medical decisions, but not other decisions.

You can say exactly what decisions you want your power of attorney to make for you. A power of attorney might cover only health care decisions, but it can also cover other things, like money, property, or making contracts. You can choose more than one person to be powers of attorney for you. You can specify what powers each one has.

You can revoke or undo the power of attorney at any time if you no longer want them to make decisions for you or act on your behalf.

Exploring Decision-Making Supports for Health Care

Have discussions with your family, friends, and other supporters about what kind of decision-making supports you may need. Work with your supporter to complete the **Exploring Decision-Making Supports** for **Health Care** tool.

You can find and download the Exploring Decision-Making Supports and Tip Sheet in the resource section.





To learn more about SDM and other decision-making supports, see the EZ-Reader: Understanding Your Legal Rights: Supported Decision-Making. It can also be found in the Resources section.



LEARN, TALK, DO. FOR SUPPORTERS

Learn. Talk. Do. For Supporters

Read through the Side-By-Side Guide and EZ-Reader with the youth. If there are things they do not understand, try explaining it using different words or in smaller bites. Answer any questions they might have. Use real life details to illustrate points. Stop and share stories or details as you go.

Health Care Rights





🔞 Learn

Together, read the information on health care rights in this guide. Then select a few websites about health care rights in the resource section and either watch the videos or read through the information together.



Talk

Have a discussion with the youth about what kinds of things in their health care they want to keep private, and what they might agree to share. Share some of your own experience about the kinds of information you chose to share with others, and who you are comfortable sharing it with.



Do.

Assist the youth with making a list of accommodations they may need for regular health visits or emergencies. If they would like easy access to a list of accommodations, help them explore the best way to do that (medical ID, health app, printable or electronic list, etc.).

Help the youth focus on listing any alternate formats that will help them understand and process information or make decisions. What would be helpful for health care professionals to understand about how they communicate, especially in times of stress?

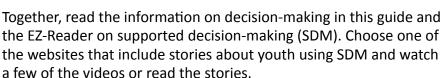


LEARN. TALK. DO. FOR SUPPORTERS

Decision-Making











Discuss with the youth what they learned from watching the videos or reading the stories. What were things that stood out to them when reading about or watching the youth talk about SDM? Encourage the youth to talk about the different kinds of health care decisions they may need to make as an adult. Some examples of questions to ask include:

- Who do they think would be good supporters for them when using SDM?
- What are ways they might like to be supported?
- Are they worried about making health care decisions?
- What do they think might be hard to decide?

Moving to Adult Health Care: Understanding Your Legal Rights

LEARN. TALK. DO. FOR SUPPORTERS

Decision-Making (continued)



This tool is to help you and your supporters explore where and why you might need support when making decisions about your health and health care. You can fill it out yourself or use it to have discussions with family finded and other supporters.				
discussions with family, friends and other supporters. 1y Name:	Date:			
upporter's Name (if needed):				
elationship to person (check one): Self Family Friend Guardi	an Other:			
low long have you known the person?				
For each question below, mark the level of support you need when making and communicating decisions and choices for health care and healthy living.	I can decide with no extra support	I need support with my decision	I need someone to decide for me	
Do I choose when to go to the doctor or dentist?				
Do I decide/direct what doctors, medical/health clinics, hospitals, specialists, or other health care providers I use?				
Can I make health/medical choices for my day-to-day well-being (check-ups, routine screening, working out, vitamins)?				
Can I make medical choices in serious situations (surgery, big injury)?				
Can I make medical choices in an emergency?				
Can I take medications as directed or follow a prescribed diet?				
Do I know the reasons why I take my medication?				
Do I understand the consequences if I refuse medical treatment?				
${\sf Can\ I\ alert\ others\ and\ seek\ medical\ help\ for\ serious\ health\ problems?}$				
Do I make choices about birth control or pregnancy?				
Do I make choices about drugs or alcohol?				
Do I understand health consequences associated with choosing high risk behaviors (substance abuse, overeating, high-risk sexual activities, etc.)?				
Do I decide where, when, and what to eat?				
Do I understand the need for personal hygiene and dental care?				
The full CtLC Tool: Exploring Decision-Making Supports, covering all life				



Assist the youth to fill out the **Exploring Decision-Making Supports for Health Care** tool.

The tool is a chance to have conversations with the youth about what decisions they can make on their own and where they might need help. The youth can involve other people they know and trust in this conversation as well.



Moving to Adult Health Care: Understanding Your Legal Rights

ADDITIONAL RESOURCES

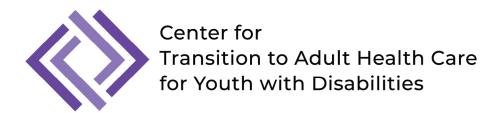
Resources

- Got Transition Turning 18: What it Means for Your Health gottransition.org/resource/?turning-18-english
- Charting the Life Course Healthy Living: Exploring Decision-Making Supports for Health Tool and Tip Sheet https://umkc.canto.com/b/VQ009
- Charting the LifeCourse: Supported Decision-Making Information and Tools
 www.lifecoursetools.com/lifecourse-library/exploring-the-life-domains/supported-decision-making/
- HealthIT.gov Your Health Information, Your Rights www.healthit.gov/sites/default/files/YourHealthInformationYourRights_Infographic-Web.pdf
- U.S. Department of Health and Human Services: Office of Civil Rights: Video- HIPAA Rights www.youtube.com/watch?v=FKTHncn-5Vs
- U.S. Department of Health and Human Services: Office of Civil Rights: Video Communicating with Family, Friends, and Others Involved in Your Care www.youtube.com/watch?v=om2IPAcADas
- U.S. Department of Health and Human Services: Video Your Health Information, Your Rights www.youtube.com/watch?v=3WsRzlutBQk
- Center for Youth Voice Youth Choice (CYVYC) Youth tell their stories about SDM youth-voice.org/stories-of-supported-decision-making/
- CaringInfo Power of Attorney and Caregiving www.caringinfo.org/planning/advance-directives/power-of-attorney-and-caregiving/
- Advocates as Leaders Self Advocacy Speaker's Network Utah: Supported Decision-Making, An Alternative to Guardianship selfadvocacyinfo.org/wp-content/uploads/2019/06/Support-decision-making-Guide-revised-2018.pdf



Scan the QR Code with your mobile device to visit the resources listed above.





The Center for Transition to Adult Health Care for Youth with Disabilities is a national health care transition (HCT) resource center. The goal of the center is to empower youth and young adults with intellectual and developmental disabilities (ID/DD) ages 12-26 to direct their own transition from pediatric to adult care with no reduction in quality of care of gaps in service.

movingtoadulthealthcare.org/toolkits/







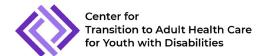


Developed by:



This project is supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$2,425,000 with 100 percent funding by ACL/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.

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Understanding Your Legal Rights:

SUPPORTED DECISION-MAKING



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What Is This and Who Is This For?

This is one in a series of six booklets. They are meant to help you learn about moving to adult health care and healthy living.

This EZ-Reader, **Understanding Your Legal Rights: Supported Decision-Making**, is to help you learn about making your own decisions when you are an adult. It is about how you can choose friends, family, and others to help you with making decisions.





EZ-Readers use words and pictures to help you understand what you need to know.



You can read this booklet by yourself.



You can ask someone to read it with you.





When you are a young child, your parents make most of your decisions for you.

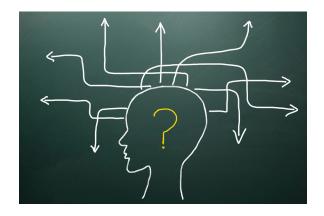


As you get older, you can learn and practice making choices.



As you get more chances to practice, you will be more prepared to make adult decisions.





When you are an adult there are many things you may need to decide.



You might decide big things like:

- Where you live
- What kind of job you have
- What you do with your money



You may also decide other things like:

- What to eat
- What to wear
- Your daily routine
- Who you spend time with





As an adult you will make decisions about your health.





Some things you may decide are:

- What doctor you want to see.
- Whether or not you want a medication or medical treatment.
- Who you want to share your medical information with.
- Who (if anyone) you want to go with you to doctor or health care visits.





Sometimes, you may need help making decisions.



That is how it is for anyone.



We all need help or advice sometimes to decide.





We ask people that we know and trust for support.



We often ask family or friends.



We choose people who know something about the issue or topic.





People with disabilities may need extra help with decisions.



With good support, they can make decisions and control their own lives.



Supported decision-making is one way to get that help.





Supported Decision-Making means you make your own decisions with help from others.



You choose who you want to help you with decisions.



You can choose people you know and trust.





The people you choose are called **supporters.**



Supporters do not make decisions for you.



They help you so you can make your own decisions.





Supporters can help you understand what you need to know.



They may explain things in a way that is easier to understand.



They can help you find and get information you need to make your decision.





Supporters can explain your options.



They may help you talk about what is good or not good for each options.



They can give you advice about what they think you should do.





Supporters can help you make a list of questions to ask.



Sometimes you might have trouble telling others what you want.



Supporters can help you tell others what you decide.





Supporters can help you at your health care visits.



They can talk with you about what is good or risky about health choices.



They may help you learn if taking a certain medication might help you or hurt you.

Communicating with Health Care Workers



Supporters can help if you are not easily understood.



They can help the doctor understand what you are saying.



Your supporter can tell the doctor or health care worker what you decide.





You can make a supported decisionmaking plan where you write down who you want to help you make decisions.



Your plan can say what decisions your supporters can help you with.



You can also ask people you trust for help with decisions when you need it.





Research shows that people with Intellectual and Developmental Disabilities (IDD) who have used supported decision-making say:

- They are more independent.
- They feel good about making decisions.
- They can make important decisions.
- They feel good about their lives.

From: "I learned that I have a voice in my future" Summary, Findings, and Recommendations of The Virginia Supported Decision-Making Pilot Project by Martinis, J. & Beadnell, L. (2021)





When using supported decision-making, you decide who you want to help you with decisions.



You decide how you want people to help you.



You make the final decisions.



Charting the Life Course Healthy Living: Exploring Decision-Making Supports for Health Tool and Tip Sheet

umkc.canto.com/b/VQ009

Advocates as Leaders Self-Advocacy Speakers Network Utah - Supported Decision-Making an Alternative to Guardianship: A Self-Advocate's Guide to Supported Decision Making selfadvocacyinfo.org/wp-content/uploads/2019/06/Support-decision-making-Guide-revised-2018.pdf

Charting the LifeCourse: Supported Decision-Making Sample Agreements www.lifecourse-library/exploring-the-life-domains/supported-decision-making/

Self-Advocate Coalition of Kansas: Supported Decision Making and Taking Care of Your Health www.youtube.com/watch?v=uo6m6cNZHpw

Center for Youth Voice Youth Choice (CYVYC) Video - Derek Heard's Supported Decision-Making Journey

icimedia.wistia.com/medias/s26egmca0d

National Resource Center for Supported Decision-Making – Click on the map to find information about SDM in your state.

supporteddecisionmaking.org/in-your-state/

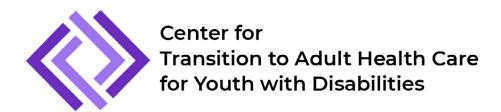
Center for Public Representation (CPR) - 8 stories about using Supported Decision-Making supporteddecisions.org/stories-of-supported-decision-making/

The Arc: Center for Future Planning - Making My Own Healthcare Decisions thearc.org/wp-content/uploads/2019/07/Making-My-Own-Health-Care-Decisions--A-Letter-for-to-My-Doctors.pdf



Use this QR Code to visit the links listed in the resources above.

This is one of six Health Care Transition EZ-Readers. Check out movingtoadulthealthcare.org to find the EZ-Readers and other resources (Side-by-Side Guides, Tools).



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movingtoadulthealthcare.org/toolkits/









Developed by:



Training and Technical Assistance Center
UMKC Institute for Human Development • UCEDD

his against is a supported by the Administration for Community Living (ACL) 11C. Department

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Healthy Living | Exploring Decision-Making Supports for Health

This tool is to help you and your supporters explore where and why you might need support when making decisions about your health and health care. You can fill it out yourself or use it to have discussions with family, friends and other supporters.

My Name: Date:					
n Other:					
How long have you known the person?					
I can decide with no extra support	I need support with my decision	I need someone to decide for me			
	I can decide with	I can decide with I need support			

*The full CtLC Tool: Exploring Decision-Making Supports, covering all life domains, is available at: www.lifecourse-library/exploring-the-life-domains/supported-decision-making/





Exploring Decision-Making Supports for Health | Tip Sheet

Overview

There are many decisions you will make about your health care. Some decisions you may make by yourself. Some decisions you may want help with or want someone to make for you.

This tool can help you:

- Think about what help you might need when making decisions about your health care.
- Figure out when you will need help with health care decisions.
- Talk about how others can best help you.

How To Use It

You can fill this out by yourself, or gather some family, friends, or others that you trust to talk about it with you. Have conversations to explore the choices and decisions about your health and health care needs. Talk about how much support you may need.





If you can make that decision with no extra help, put an X in the blue column.



If you think you can make the decision with help, put an X in the purple column.



If you think you **need someone to decide for you**, put an X in the green column.



If you don't think the question applies to you at all, then you can cross it out.

- Do you have any X's in the purple column? If so, would supported decision-making or another alternative to guardianship help you make that decision?
- Do you have any X's in the green column? If so, can you use a power of attorney or another alternative to give someone you trust the ability to make the decision for you? What skills would you need to learn or practice to be able to make the decision for yourself?