



















Strong and Growing:

A Health Care Transition Guide for Young People with Chronic Health Conditions



This Guide Is About You

You are the expert on your own health. You live every day with a chronic health condition or disability. And this experience gives you unique knowledge and strength.

This guide is here to help you be your healthiest self. It's also here to help you:

- · Think about who you are and what matters to you
- · Ask for what you want and need
- Make choices that work for you
- Do more of the things you enjoy—now and in the future

Our goal is to help you grow strong and confident.



What Does That Word Mean?

Let's start by defining a few words and terms you may come across in this guide or when talking about health. These words describe people of all ages, genders, races, religions, and backgrounds.



Advocacy: Speaking up for yourself or others to ask for what you need. It's also about supporting someone else's needs or supporting something that will make things better for yourself or others.



Autonomy: Learning to make choices, ask for help when you need it, and be part of the decisions about your care, school, and future. Autonomy means having a say in what happens to you and being able to do things in a way that works best for you. Everyone's autonomy is personal and may look different, there isn't just one right way.



Chronic: Diseases or conditions that last 1 year or more and require ongoing medical attention or limit activities of daily living or both. This definition comes from the Centers of Disease Control.



Disability: A condition that may shape how someone plays, learns, or connects with friends. Sometimes it means using different tools or supports to make those activities easier.



Disability identity: A person's sense of self as someone with a disability. It's often about personal, lived experience, and meaning. It can also include a sense of belonging and connection with the wider disability community around them.





Family: This word refers to the people you feel close to and who support you. It can be parents, siblings, grandparents, or relatives, but it can also be friends, neighbors, caregivers, or other trusted adults you choose to count as family.



Health condition: This term can cover many things like disability, long-term illness, behavioral health or even mental health. Some people and health-related organizations use the term children and youth with special healthcare needs to describe this.



Health literacy: The ability to find, understand, and use health information to make timely decisions about your health.



Healthcare Transition (HCT): The shift from having family making most decisions to making more choices for yourself. The amount and types of choices you make for yourself may be different than someone else's, even someone else with the same chronic health condition or disability as you. Some examples that may or may not directly apply to you can include learning how to manage your health, school, work, finances (money), meal preparation, and relationships. Learn more about the difference between pediatric and adult care.



Mental health: This is about how you feel, think, and act. It includes your emotions, habits, and how you handle stress or problems and relationships. Taking care of your mental health is just as important as taking care of your body.



Neurodivergent: A word for people whose brain works in different ways than a neurotypical person's.



"Normal": People use this word a lot. But there's no single way to be normal or have a normal experience. That's why there are quotation marks around this word. Everyone is different and so are their medical needs, daily activities, or pain and symptoms. What's normal or typical for you may be different for someone else.



Pediatrician: A doctor trained to take care of babies, children, and young people up to age 21.



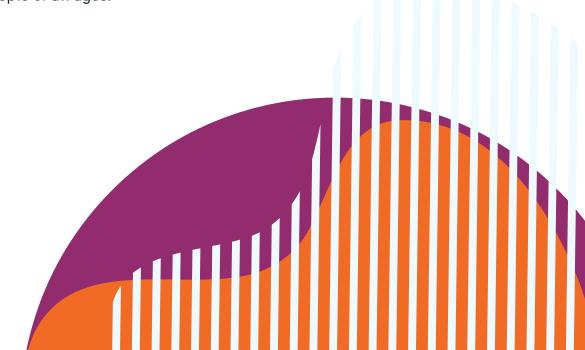
Primary Care Provider (PCP): The main doctor or nurse you go to for regular check-ups, when you are sick, or when you have questions about your health. They help you stay healthy and can send you to a specialist if you need more help.



Specialist: A doctor who focuses on a specific part of the body or a single type of health problem, like a heart doctor or an allergist.



Tween, teens, adolescents, youth, young people: These are different words to describe people ages 9 to 24. This guide is made for anyone who finds it helpful, including people of all ages.





Let's Get Started

This guide is for kids and teens at different stages, not just a particular age or grade. Everyone grows and learns at their own pace. No matter how old you are, this guide can help you think about what's ahead.

Whether you just started middle school or you're getting ready for high school, you've probably noticed that life is different from when you were younger. It's a good idea to think about what's changed, what's important to you, and what you want as you grow up.



Thinking about the future might feel scary. That's OK. The future doesn't happen all at once. When you start early, you have more practice and can make choices that work for you.

As you get older, some of the help you have now might change. For example, you might switch from a pediatrician to an adult doctor. You might also receive less support at school or from your care team.

This is sometimes called a "service cliff." It can start after high school, when the systems and support around you start to switch.

That's why it's important to plan before that switch happens. Talking with your family, teachers and doctors can help make sure you continue getting the help you need as you grow up. It helps you keep up with preventive care—regular care that keeps your body healthy and can help catch problems early.



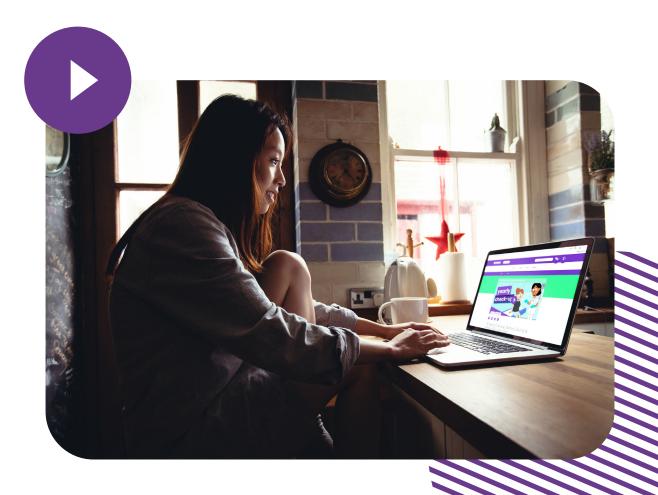
What is Preventive Care?

Preventive care means going to the doctor, dentist, or other helpers **even when you're not sick.** It includes things like:

- Vaccines
- Teeth cleanings
- · Eye and hearing checks
- · Health screening and regular check-ups

These visits help catch problems early, so you can keep doing the things that matter to you. Young people and families can learn what to expect and how to prepare by visiting the Personal Safety: A Yearly Checkup: <u>Before, During & After a Doctor's Visit – amaze page.</u>

Young people who have Medicaid are covered up until age 19 in Washington State. Learn more here: Children | Washington State Health Care Authority.



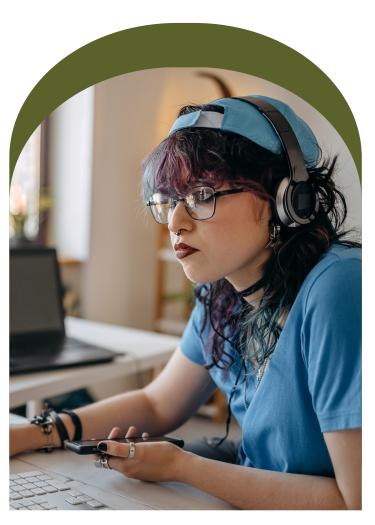


Ready to Take Charge?

Let's start by practicing a few health literacy skills. Remember, health literacy means being able to find, understand, and use health information to make timely decisions about your health. You don't have to learn everything at the same time. Start small and build confidence in a way that works for you.

Here are 3 ways to begin:

- 1. Know your condition. Learn its name (and nickname, if there is one). Share it only with people you trust.
- 2. Track your medications. Write down the names, allergies, when, why, and how much you take.
- **3. Explain your care.** Practice saying what you do daily to stay healthy—like using a device, going to appointments, or doing therapy.



Tips to Make it Easier:

Here are some things that can help you stay organized with your health:

- Set or write reminders on your phone, tablet, or your binder for when to take your medications. You can also save your medical history in your health settings, so paramedics can find it in an emergency.
- Try health apps. Some apps can help you track symptoms, pain, and medications.
 Others can help schedule a doctor's visit or connect with your doctor or pharmacy. Make sure to check the privacy rules with an adult before adding a new app.
- Bring this guide to your next doctor's appointment. You can also use a computer document or a notebook to keep track of your information.
- Ask questions if you don't understand something. Medical talk can be confusing and asking your health team for clarification can help.
- If it helps to have a visual explanation, ask for it. If you already know what kind of support helps you learn best, let your care team know. It's a great way to advocate for yourself.
- It's OK to go slow and make mistakes. You're learning, and that takes time.



Ready to Do More on Your Own? Take Charge of Your Health

If you want to go on a school trip, hang out with friends, or stay overnight somewhere, it helps to know how to take care of your health needs or how to ask for help with them.

Start with small steps. Pick a few things from this list that you're ready to try:

- 1. Take my medications when I'm supposed to.
- 2. Tell someone when I need a refill on my medications and ask them to help me order more.
- 3. Make my own doctor's appointment by calling, texting or checking my online medical chart.
- 4. Fill out medical forms with help so I can learn my medical history.
- 5. Learn more about my health condition(s) by reading or asking questions.
- 6. Look up health information on trusted websites. It's OK to ask for help from a teacher, caregiver, or other trusted adult to make sure the site is safe.

How do you know if a health-related website is safe?

Some websites are more trustworthy than others. Search for sites that end in:

- .gov "like from the government, such as doh.wa.gov, CDC.gov, or NIH.gov
- .org from some trusted organizations like KidsHealth.org
- .edu from schools and universities

Privacy and confidentiality

It's a good time to think about your privacy and who you want to share your medical history with in the future. Discussing confidentiality is important. Confidentiality means that your private health information is kept safe and shared with only people you want it shared with. Ask your doctor how this works with your medical records.

Tip: Check out <u>doh.wa.gov/teenhealthhub</u> for trusted and teen-friendly information. Health-related information on these sites is more likely to be accurate and reliable.

Safe Tech Tip: Someday soon, you might be able to use AI (artificial intelligence) to make future doctor appointments!

Your Turn

What are some things you think you could start doing on your own? Use this space to write, draw, or sketch.



Being a Teen Can Feel Like a Lot

Being a teen can be awesome and tough at the same time.

You're meeting new people, trying new things, and learning how to do things on your own. There's also a lot of change happening. If you live with a chronic health condition, it might feel like you have even **more** to manage.

You're not alone. Lots of other young people feel this way too.

Something that can help? Keeping a journal or things like playing video games, photography, listening to music.

You can:

- Write in a notebook, type on your phone or tablet, or record voice notes
- Listen to music
- Practice art
- Garden outside

Sometimes it helps to get your thoughts and feelings out to make things feel less overwhelming.

Journaling may help you:

- Cope with stress and big feelings
- · Stay focused on your goals for school, friends or managing your health
- Celebrate your progress (because even small stuff matters!)

Try these journal prompts:

- I. What made me laugh or feel happy this week?
- 2. What helps me cope when things get hard?
- 3. What do I wish others knew about my health?
- 4. What 3 songs match my mood this week?
- 5. Have I ever felt different around my friends? What made me feel left out?
- 6. How can I get involved or advocate for something I care about, like a cause or my community?



Below are some examples to think about:

Consider speaking with a counselor or a trusted adult if your feelings become too big to handle on your own. Sometimes it can be difficult to meet the social, emotional, mental, and other demands during this period. It's OK to reach out for help!





Growing Up with a Chronic Health Condition

Taking care of your health as you grow is a big deal, and you are not alone. Lots of young people with long-term health needs have found ways to create a life that works for them.

Planning ahead can help make the switch from pediatric to adult health care go more smoothly. These conversations should start early, before you turn 18, because it takes time to figure out what kind of care you'll need and where you'll feel most comfortable.

Talk with your family and doctor about:

- · Where you go for adult health care may depend on your health condition.
- What kind of specialist support or care you'll need
- If you can visit or contact a new clinic to check what they're like and ask questions. It's
 important to make sure your doctor and health team understand your health condition and
 are compassionate toward what you need.

Learning the skills to be involved in your health takes time. It can be exciting, but also a little overwhelming.

For now, support from your family is really important.

Trying to stay positive during the frustrating moments is part of learning to live life to your fullest potential.

You've got this.







Where to Find More Support Now

In school, you have the right to get extra support if you need it. Two tools this can happen are through something called a 504 Plan or an Individualized Education Program (IEP). These plans make sure you get the tools, services, or changes you need like extra time on tests, help with notetaking, or other supports that make learning easier. Learning about them and asking questions can give you more control and confidence, and can help you feel more ready for the future. Having a plan in place can be one more way to remind yourself: things will be alright, and you're not alone in this journey.

Who is eligible?

All students with an IEP will have a Transition Plan in place by age 16. Special Education is available to eligible students from prekindergarten until the age of 22, based on the results of a comprehensive special education evaluation conducted at their school.

What does IEP Transition Plan include?

- Transition assessment
- Individualized transition services
- Relevant course of study and annual IEP goals
- Coordinated services with adult agencies
- Appropriate and measurable postsecondary goals



Washington State Transition Map | WSRC

Transition services and supports.



Health Habits

If you have a chronic health conditions like epilepsy, autism spectrum disorder (ASD), type 1 diabetes (T1D), attention deficit hyperactivity disorder (ADHD), or cystic fibrosis (CF), your family may do extra things to help you stay healthy. That can take planning and teamwork!

Here are some ways families, or trusted adults, can help kids and teens with health needs.

Check off the ones your family does for you

	Tell	me	when	to	take	my	medications
--	------	----	------	----	------	----	-------------

☐ Order my medications when I need more

☐ Read books to learn more about my health conditions

☐ Schedule appointments with my doctors

☐ Take me to my medical appointments

☐ Come into the examination room with me

☐ Tell the doctors about how I am feeling

☐ Answer the questions that the doctors ask

☐ Ask the doctors questions about my condition

☐ Take notes about what the doctors say

☐ Remember what the doctors say to do

☐ Explain to me about my health conditions

☐ Look things up on the internet about my condition

Can you think of more?



Check out who your local CYSHCN Coordinator is in your community if you want more resources or help: Children and Youth with Special Health Care Needs | Washington State Department of Health



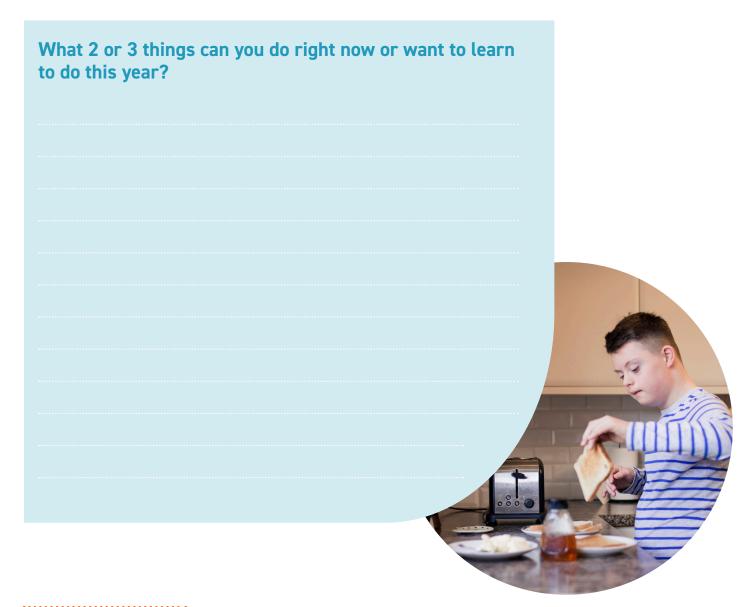
Going from Tween to Teen

As you grow, you may start keeping track of more things on your own like assignments, afterschool activities, and homework.

This shift is about learning to make more choices and living the fullest life you can. It helps prepare you for high school, a job and other future responsibilities.

Since you're already learning to take care of things in school, it's a great time to start taking on more when it comes to your health too.

Taking charge: On the previous page, you checked off a few things your family or other supportive people in your life does now to help you be healthy.

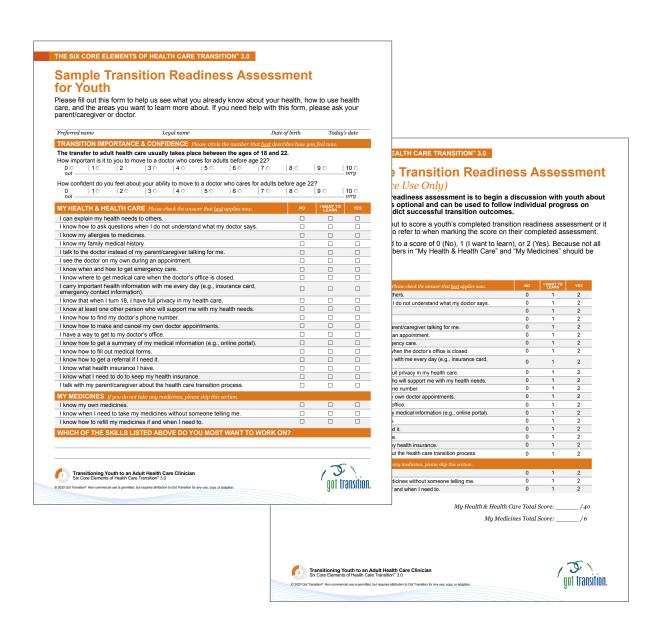




Getting Ready to do More

Let's review your skills! This page has a tool called a <u>Sample Transition Readiness Assessment for Youth</u> from Got Transition. It helps you figure out what you already know about your health, how to use health care, and what you might want to learn next.

Bring this guide to your next doctor's appointment. You can talk about what you want to work on.





Let's think about the things you're learning to take care of at home and at school.

It's important to build independence, learn how to advocate for yourself and ask for support when you need it. Think about what happens when things go well or when they don't.

Things I'm Learning to Do	At Home	At School
Support that Helps Me (tools, people, or strategies)		
When I Do Well (results or rewards)		
When It's Tough (challenges or obstacles)		
Fair or Not? (Do I think that's fair? Why/why not?)		



Imagine Your Future

Your future is yours to shape, and everyone's path looks different. This page helps you think about the adult life you want. There are no right or wrong answers. Planning takes time, so it helps to stay flexible.

What do I want for my future? Use this chart to write down your own ideas.

Learning and Work	Where I Might Live	How I Might Live		
I want to go to high school:	I might live in my own apartment or house (alone or with others):	I want to manage my own money and bills (with or without support):		
Yes \square Maybe \square No \square	Yes □ Maybe □ No □	Yes □ Maybe □ No □		
I want to finish high school:	I might live with family (parents, siblings, or relatives):	I want to learn how to get around (bus, ride apps, or drive):		
Yes □ Maybe □ No □	Yes □ Maybe □ No □	Yes □ Maybe □ No □		
I want to go to college, trade school, or get job training: Yes Maybe No	I might live with in-home help or somewhere where I can get extra support. This can mean having someone come help you with some things or living in a group home. Yes Maybe No	I'd like to have a close friend or partner someday: Yes □ Maybe □ No □		
I want to have a job when I'm an adult: Yes Maybe No	I might live on my own (alone or with others) close to my job or close to my support system. That way I can get to work easier or get family support when I need it. Yes Maybe No	I want to care for a pet or emotional support animal: Yes Maybe No		
Jobs, training, or community centers I'm interested in: (write here)	I might use certain government benefits or funds to pay for my housing and transportation. Yes Maybe No	I want to stay connected to friends and people I care about: Yes Maybe No		



Helping Your Family Step Back (Just a Little)

It might feel hard for you and your family to think about switching to adult health care and using more health skills on your own.

You may have been with the same pediatrician for a while. And your family, or other supportive person, may have been by your side through every appointment. Sometimes, parents have a tough time when their child starts doing more on their own, especially when it comes to health stuff.

But as you grow up, things change. By age 18, you're a legal adult and responsible for making decisions about your health care. This big change can feel exciting and a little scary.

Your family might be nervous too. They may worry if you'll be able to understand medical decisions or be comfortable learning a new health care system. That's totally normal.

Planning and practicing early can help everyone feel more confident.

Ask your doctor how to access your Electronic Medical Records (EMR), like My Chart.

Before you turn 13

set up preferences for what information you want shared with your family.

After you turn 13

You get to decide who has access to your medical records and health care information.

Your doctor or clinic staff can help you set this up.



Here are some ways to share what matters to you and be part of decisions about your care and daily life:

Talk about it.

Try saying:

"I want to practice doing this by myself, but I still want your help when I need it." This helps your parent or caregiver know you're growing—not pushing them away.

Make a plan together.

Pick 1 thing to take the lead on like your schedule, routines, or activities. Ask your family to support you by stepping back a little while you try it.

Show what you can do.

Tell your doctor something about your health or ask questions at your next appointment. Or pack your own bag or get your documents ready. Small wins show your family that you're learning and builds trust and confidence.

Ask for "practice time."

You could say, "Can I try doing this while you're there, just to practice it?" This gives you a chance to build skills, with help close by.

Ideally, you and your support system are a team.

And like any good team, everyone has a part to play. Trying small things now can help you all feel more ready for what's next.





Talking with Your Doctor

Now that you've learned more about your health, you can practice what to say at your doctor visits. It helps to practice and still ask for support when you need it.

Here are some things to try on your own or with an adult you trust:

Before you go

- Carry your insurance card or medical ID.
- Know why you're there (annual checkup, follow-up, etc.).

Check in at the front desk

You can do this with help if you need it.

During the visit

- Ask to spend part of the visit alone with your doctor. Even just a few minutes on your own helps build confidence.
- Choose to answer 1-2 questions in your own words.
- Say how you're feeling: "I've noticed some pain in my stomach recently"

"I feel tired after lunch lately"

Share what works for you

- How you take medicine.
- How you prefer shots or vaccines.
- How you want to talk about private topics.

Understand your care

- Repeat or write down instructions.
- Ask for plain language, translation, or an interpreter if needed.

Remember: Asking questions and speaking up is a way of advocating for yourself.





Getting Answers to Your Questions

When you're alone with your doctor, you can talk about things you might not feel comfortable sharing with your family in the room.

This is your time to ask questions that matter to you. It's part of learning how to say what you need and make decisions about your health.

To help you remember:

- Write your questions before your visit
- Bring them with you to make sure you get your questions answered
- You can give them to your doctor to read or ask if they can write their answers down for you



Next time you visit your doctor, take your questions with you and ask. You can write them below to practice.

Doctors want you to have the information you need to stay healthy. They appreciate it when you take the time to think about your questions and bring them to your visit. Some doctors are also OK answering questions by email or during a virtual call. You can ask your doctor the best way to follow up after your appointment—email,

phone, or messaging through online chart.



What to Say When You're Not Sure What They Mean



Let's be honest, going to the doctor can feel confusing and sometimes tiring too.

Doctors and nurses might:

- Use big or complicated medical words
- Talk really fast or seem rushed
- · Give you too much information all at once
- Not answer your question clearly
- Expect you to remember everything they said

It's totally OK to ask questions! This is a great opportunity to practice self-advocacy.

Here are some ways to ask for help or get clearer answers:

- · "Can you say that again a little slower?"
- "Could you write that down for me?"
- "Where can I learn more about this?"

You can ask the same question more than once. You deserve to understand what's going on with your health.

Tips For Getting the Help You Need

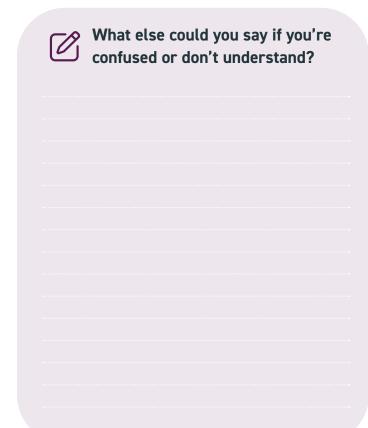
- Ask your doctor to speak to you and not just your family. It's your body and your health.
- You can ask your doctor how to follow up if you have more questions later.

Try It Out

You can practice by role-playing with your family. Try:

- Taking turns being the doctor and patient
- If you're comfortable, record your role play to watch and improve
- Giving each person a "job" (like asking, explaining, or writing things down)

Then switch roles!





Before and Now: All About Me

Let's see how you've grown!

Write, draw, or talk about what you liked in elementary school and what you like now in middle school or high school. Some things may be the same. Some might be different.

You can also share these with your doctor! Health visits don't have to be only about your health condition. You are more than your diagnosis.

	Past - Elementary School	Now
Favorite things I like to do		
Things I like about school		
My favorite music		
TV shows I love		
A book I really liked		
Subjects I'm best at		
Something I'm really good at		
Someone I would love to meet		
My favorite movie or movies		
What job or jobs I want to have when I grow up		
Something I don't like doing		



Now that You're Taking on More Responsibilities

You can mark this health care list with Yes or No, there is no right answer. It's OK if you still need help with some of them. The goal is to notice what you can do now or do with support from others.

Health Care Checklist		
Statement	Yes	No
I understand my health care needs.		
I can explain my health care needs to someone else.		
I tell the doctor(s) how I am doing and can answer their questions.		
I know the name of my doctor(s).		
I take my medicine(s) with supervision.		
I know the name(s) of the medicine(s) I take and possible side effects.		
I know when I am sick.		
I have a copy of my insurance card.		
I carry a summary of my medical information with me.		
I can schedule my own appointments.		
I can live in a home the way that I want to.		

Final words:

Transition to adult health care takes time and practice. With the support that works for you, you can create a plan that fits your life. We hope this guide can be a trusted tool that helps.



National and Local Resources to Learn More

Resources:

- Disability Organizations | Washington State Department of Health
- Got Transition® Youth & Young Adults
- Transition to Adulthood Family to Family Health Information Center
- · <u>CFI Center For Independence</u>
- Informing Families | Navigating the future
- Healthcare in Transition PAVE
- Center for Transition to Adult Health Care for Youth with Disabilities Family Voices
- Transitioning to Adult Healthcare
- Your Child With Disabilities Is Turning 18 (On-Demand Virtual Class)
- Transition into Adulthood Overview: Transition into Adulthood: Resource Guide: The Arc of King County
- The AHEAD Program UW Diabetes Institute
- Washington State Transition Map | WSRC
- Transition Hub
- Center for Change in Transition Services | Seattle University
- AUCD | Linktree

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