



Center for
Transition to Adult Health Care
for Youth with Disabilities

A Side-by-Side Guide in the **CtLC Life Experience Series**
Developed by the LifeCourse Nexus



Moving to Adult Health Care:

KNOWING ABOUT YOUR HEALTH

UMKC Institute for
Human Development
A University Center for Excellence in Developmental Disabilities

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: Knowing About Your Health**.

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 download the Toolkit Series.





Moving to Adult Health Care: Knowing About Your Health

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 lifecoursetools.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 toolkit in this series, **Moving to Adult Health Care: Get Ready for a Change**, you learned about what it means to transition from pediatric to adult health care.

In this toolkit, **Moving to Adult Health Care: Knowing About Your Health**, you will learn about understanding your own health and disabilities. You will also learn about different kinds of doctors, specialists and other health care workers you might see.





Why Learn About This?



Up until now, someone else, usually your parents or family, have taken care of knowing all about your health.

- Know all the details about any health issues you have
- Know the names of your disabilities and how it affects you
- Know about any treatments or surgeries you have had as a child
- Keep a record of your medical history and vaccines



Until now, your parents have likely kept track of all the doctors you see. They know:

- The names of all your doctors and other health care workers
- Why you see each one
- How to contact your doctors and other health workers
- How to contact your therapists
- The names of all your medications and why you take them
- How much and how often you take each of your medications

That Is a Lot

Part of becoming an adult who takes charge of their life, is knowing what your health needs are. You can start to learn about your own health and health care now. After you turn 18, you might decide you are going to do all the things that your parents have done up until now. But you do not have to do it all. You can ask family or other trusted people to help you with as much or as little as you want.



Knowing Your Health Conditions



An important part of taking charge of your health care is knowing about your own health information. You can start by having discussions with your parents/caregivers and your health care workers. Ask them about your overall health.

- There are some things everyone should know about themselves. You should learn and write down your blood type, and any previous injuries, and surgeries. You should also keep track of when they happened.
- You should find out about any ongoing or chronic health conditions you have. Chronic means having an illness that goes on for a long time. Some examples are asthma, diabetes, arthritis, or heart disease.
- You should know about any symptoms your health conditions cause. What are the ways that it affects your body or your overall health? Does it affect the way you live your life?



Knowing About Your Disability



It is also important to know as much as possible about any disabilities you have. A good way to start is by talking to your parents/caregivers, your doctors, and other health care workers about your disability. Here are some things you can ask about or discuss:

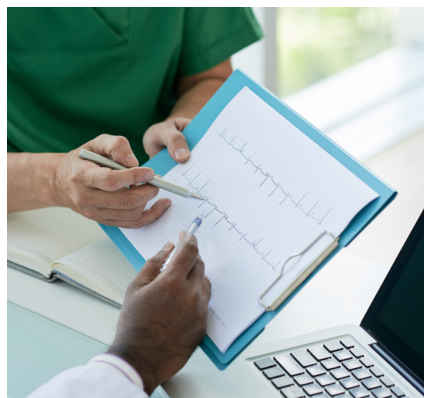
- What is the name of your disability? Do you have more than one disability diagnosis? For example, you might have both cerebral palsy and epilepsy.
- When were you diagnosed with a disability? Sometimes people know at birth. Other times a child is older when it is found they have a disability.
- In what ways does the disability affect your life? Does it affect how you learn, walk, talk, think, or breathe? Does it affect you in other areas of life (work, live independently, social life, safety)?
- What are some of the health issues you have because of your disability?
- What are some changes you might see in your disability as you get older and move through different life stages?
- What treatments or therapies have you tried? Which helped you and which did not?

The More You Know

You should understand as much as you can about your disability so you can talk to others and be able to explain it to them or answer questions. You do not have to remember everything yourself – you can make a “cheat sheet” to help remind you of key things. Or you could have a written document you can hand to someone (like a new doctor) that explains your disability.



Medical History and Records



Your doctor can give you something called a medical summary to give to your new doctors. You can also ask for copies of your medical records from your doctors and hospitals where you may have had surgeries or treatment. You should keep copies of the summary and any records as well as passing them on to your new health care workers.

It is also a good idea to have information about your family's medical history. Are there certain illnesses that run in the family that you should be aware of? Did any family members get things like heart disease at an early age? Those are things your adult doctors may want to know.

Your Doctors and Health Care Workers



As a child, you may have seen just one or two doctors, like a pediatrician, who handled many of your health needs. As an adult, you may need to see different kinds of doctors. For example, you might visit doctors for your sexual health. You might have yearly 'well-woman' or 'well-man' check-ups.

Some of these doctors are called specialists. A specialist is someone who is trained to know a lot about just one specific body part or illness.

You should know the names of the doctors and other health care workers you see. You should know why you see each one and what they do for you. It is a good idea to have a list of their names, what they do for you, and how to contact each one. This includes doctors, therapists, dentist, and mental health providers.



To learn more about different kinds of doctors and specialists, download the EZ-Reader: Moving to Adult Health Care: Different Kinds of Doctors and Specialists from the Toolkit Series.



Medications



You might take medications that help you take care of your health. You should know the names of each medicine and why you take it. You may need to share this information with your doctors. It is a good idea to keep a list with the names of each of the medicines that you take and why you take it. It is also helpful to list what time you take each medicine, how often, and the way you take it. The resource section has some examples of lists you can use to keep track of your medicines.

Things You Can Do Now



- Talk to your parent/caregiver about your overall health, disability, and family medical history.
- Write down details about your disability to help you explain it to others.
- Use the **Medical Provider List** to make a list of all the doctors you see, why you see them, and how to contact them.
- Make a list of all the medications you take, why you take them, when and how much you take.

Important:

Your health information is private. You should only share it with people who need it to help keep you healthy. Examples of people you might share health information with are:

- Doctors or health care workers
- Close family or friends who help you with your health
- Pharmacists
- Caregivers or support workers who help you regularly

You can find and download the Medical Provider List and Tip Sheet in the resource section.





► Learn. Talk. Do. For Supporters



Learn

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.



To learn more about different kinds of doctors and specialists, download the EZ-Reader: *Moving to Adult Health Care: Different Kinds of Doctors and Specialists* from the Toolkit Series.



Talk

It is important for the youth to know as much as possible about their overall health as well as their disability. They will need to share this information with others as they take a more active role in their own health care. It is hard to remember all the details about our own health, so having reminders or lists to refer to can be helpful.

- Look for opportunities to talk about their health. Each time they have a health care appointment, take some time to talk about WHY they see this provider, what kind of doctor or specialist they are seeing, and what they do. Give them time to absorb the information and ask questions.
- Explain the medications they take. Include why they take it, how often, and what it does for them or how it helps them.
- Talk with them about their disability. Include details like the name of the disability, what that means for their growth and development, and if/how it affects their overall health.
- Talk about family medical history. Are there illnesses or issues that “run in the family” like diabetes or heart disease?



► Learn. Talk. Do. For Supporters



Do.

Help your youth start a notebook or folder (paper or electronic) with important medical and disability information. This is a great chance to have a discussion that will help them learn as well as create tools that will assist them as they move into adult health care. Things to consider include:

- Health summary from current doctors, specialists or pediatrician
- Medication list (why they take it, what dose, times, etc.)
- Basic health information (blood type, height/weight, diagnoses)
- Health history (surgeries, treatments, etc.)

Important Reminder: Be sure to keep these documents in an accessible, private location to be easily updated as needed.



Learn. Talk. Do. For Supporters

Healthy Living | Medical Provider List

This Belongs To: _____

Date: _____

Type of Medical Provider:	Name of Provider/Practice	Phone Number	Email	Why Do I See Them?
Ex: Specialist - Cardiologist	Ex: Dr. Smith	Ex: 555 - 555 - 5555	Ex: mydoctor@doctor.com	Ex: Takes care of my heart
Primary Doctor				
Primary Doctor				
Specialist Type:				
Specialist Type:				
Specialist Type:				
Specialist Type:				
Hospital				
Urgent Care				
Pharmacy				

Charting the LifeCourse Framework and Tools

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Do.

Assist the youth to complete the tool **LifeCourse Healthy Living: Medical Provider List**.

This tool is designed to help the youth or young adult have a quick reference of the health care providers they visit, their contact information and to understand why they see each one. As it is being filled out, it is a great opportunity to have conversations about what each provider does, and why the person sees them. This tool can be filled out over time and updated as needed.



ADDITIONAL RESOURCES

► Resources

- Charting the LifeCourse Healthy Living: Medication List and Tip Sheet
<https://umkc.canto.com/b/RGJTU>
- Charting the LifeCourse Healthy Living: Medical Provider List and Tip Sheet
umkc.canto.com/b/PKIOJ
- Self-care assessment for Youth with ID/DD and their Parents/Caregivers
gottransition.org/6ce/?staying-self-care-assessment
- Sample Transfer of Care Checklist
gottransition.org/6ce/?leaving-transfer-checklist
- Sample Medical Summary for Youth with ID/DD
gottransition.org/6ce/?leaving-medical-summary-emergency-plan
- Sample Plan of Care
gottransition.org/6ce/?leaving-plan-care
- The “Medical ID” Feature on Apple’s Health App
gottransition.org/resource/?setting-up-medical-id-smartphones
- Transition readiness assessment for Youth with ID/DD and their Parents/Caregiver
gottransition.org/6ce/?leaving-readiness-assessment-parent



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





Center for Transition to Adult Health Care for Youth with Disabilities

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 or gaps in service.

movingtoadulthealthcare.org/toolkits/



Developed by:



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Training and Technical Assistance Center

UMKC Institute for Human Development • UCEDD

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An EZ-Reader in the **CtLC Life Experience Series**
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Knowing About Your Health: **DIFFERENT KINDS OF DOCTORS & SPECIALISTS**



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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, **Knowing About Your Health: Different Kinds of Doctors and Specialists**, is to help you learn about the different kinds of doctors you see now or might see as you get older. It is meant to help you understand what each kind of doctor or health care worker can do for you.



How to Use the EZ-Reader



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.



Knowing About Your Health



An important part of becoming an adult is knowing about your own health care.



You should learn about your different health conditions and your disability.



You can start to learn about different kinds of doctors and health care workers and what they do.



Different Kinds of Doctors



There are different kinds of doctors and health care workers.



You might already see different doctors for different things.



It is important that you know about the kinds of doctors you see now and might see as an adult.



Pediatrician



A **pediatrician** is a doctor who specializes in taking care of babies, children, and youth.



They keep you up to date on checking for health issues and routine shots.



They check to see if a child is on track with their physical and mental development.



Family Physician



A **family physician** is a doctor that treats people for many different things.



They give health care to people of all ages. They see children and adults.



Sometimes they are called a **general practitioner**.



What Do They Do?



You can see a family doctor for regular check-ups. They make sure you are doing okay.



A family doctor can also see you when you are feeling sick.



They treat many common things like colds, flu, or minor injuries.



Internal Medicine



An **internist**, or **internal medicine doctor**, mainly treats adults.



They might also see older teens who will soon be adults.



They give the same kind of care as family physicians.



What Is a Specialist?



You might also see another kind of doctor called a **specialist**.



A specialist can help you with more specific health issues.



They are trained to know a lot about one type of illness or part of the body.



Pediatric Specialists



As a child you might have been seen by **pediatric specialists.**



They specialize in treating one type of illness or body part in children.



When you are an adult, you will see specialists that treat adults.



Examples of Specialists



One kind of specialist you might see is a **surgeon**.



They treat conditions that might need an operation.



Some surgeons focus on just one body part or area.



Examples of Specialists



An **orthopedic doctor** takes care of your bones and muscles.



A **neurologist** takes care of the brain and nervous system.



An **oncologist** treats cancer and other growths.



Examples of Specialists



A **cardiologist** takes care of your heart.



A **pulmonologist** takes care of your lungs and breathing.



An **ophthalmologist** is a doctor who takes care of your eyes.



Examples of Specialists



A **dermatologist** takes care of your skin, hair, and nails.



An **endocrinologist** takes care of your hormones, and sees people who have diabetes or thyroid issues.



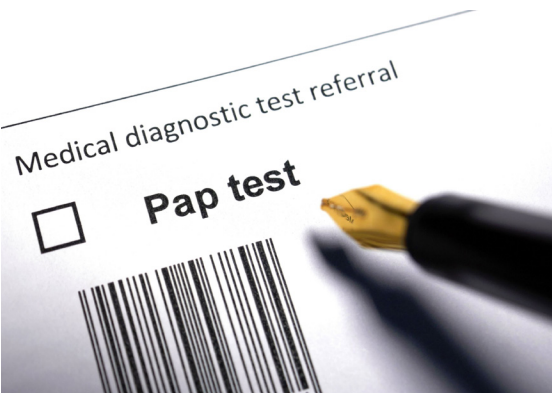
A **gastroenterologist** takes care of people who have stomach, bowel, and colon issues.



Reproductive Health



A **gynecologist** is a doctor you see for your regular well-woman visit.



They do a pap-test and exam to make sure your uterus and ovaries are healthy.



They are often also an **obstetrician**. That means they see pregnant women and deliver babies.



Nurse Practitioner and Physician Assistant



You might see a nurse practitioner or physician assistant at the doctor.



A **nurse practitioner** is a nurse who has extra training to do more things, like prescribe medication or give a diagnosis.



A **physician assistant** does many of the same things as a nurse practitioner. They can also do some medical procedures like help with surgery.



Physical Therapist



You might also see other kinds of health care workers.



A **physical therapist** can help improve your movement or manage pain.



You might see one after you have surgery or an injury.



Other Therapists



An **occupational therapist** helps with your ability to do daily living things.



They try to help you be able to live as independently as possible.



A **speech therapist** helps you to communicate better or to speak more clearly.



Mental Health



A **psychiatrist** is a medical doctor who treats mental, emotional, and behavioral disorders.



They can prescribe medication for mental issues, like when the mind feels unhealthy and things feel harder.



A **psychologist** also treats mental health issues but does not prescribe medication.



Know Your Specialists



It is important for you to know what specialists you have been seeing until now.



You will need to find out if they can keep seeing you when you are an adult.



You might need to find new specialists that see adults.



Resources

Charting the LifeCourse Healthy Living: Medication List and Tip Sheet

This tool will help you keep track of your medications, why you take them and more.

umkc.canto.com/b/RGJTU

Charting the LifeCourse Healthy Living: Medical Provider List and Tip Sheet

This tool will help you keep track of your medical providers, why you see them and more.

umkc.canto.com/b/PKIOJ

25 Types of Doctors & what they do for Patients' Health - Good Housekeeping

www.goodhousekeeping.com/health/wellness/a33863644/types-of-doctors/

What are the Different Types of Doctors?

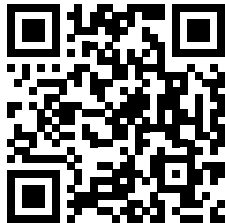
www.webmd.com/health-insurance/insurance-doctor-types

Types of Doctors – 20 Types of Specialists

www.youtube.com/watch?v=SwOph2acW7M

SKOOLL – Which Doctor Treats What Disease?

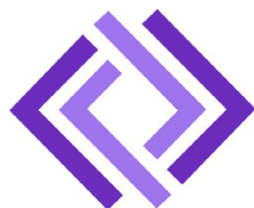
www.youtube.com/watch?v=Ku_iqEElWIA



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 lifecoursetools.com/health-care-transition to download the EZ-Readers and other resources (Side-by-Side Guides, Tools).



Center for Transition to Adult Health Care for Youth with Disabilities

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Healthy Living | Medical Provider List

This Belongs To: _____

Date: _____

 Type of Medical Provider:	 Name of Provider/Practice	 Phone Number	 Email	 Why Do I See Them?
Ex: Specialist - Cardiologist	Ex: Dr. Smith	Ex: 555 - 555 - 5555	Ex: mydoctor@doctor.com	Ex: Takes care of my heart
Primary Doctor				
Primary Doctor				
Specialist Type:				
Specialist Type:				
Specialist Type:				
Specialist Type:				
Hospital				
Urgent Care				
Pharmacy				



Healthy Living | Medical Provider List

 Type of Medical Provider:	 Name of Provider/Practice	 Phone Number	 Email	 Why Do I See Them?
Ex: Specialist - Cardiologist	Ex: Dr. Smith	Ex: 555 - 555 - 5555	Ex: mydoctor@doctor.com	Ex: Takes care of my heart
Psychologist or Psychiatrist				
Dentist				
Physical Therapist				
Occupational Therapist				
Speech/Language Pathologist				
Other Therapist Type:				
Other:				
Other:				
Other:				



Medical Provider List | Tip Sheet

Overview

You might see different types of medical providers. Medical providers include doctors, specialists, nurse practitioners, therapists, and others. It can be hard to keep track of each provider's contact information.

This medical provider list can help you:

- Keep track of your medical provider's contact information.
- Know why you see each medical provider.
- Share the information with people who need it to help keep you healthy.

How To Use It

Healthy Living | Medical Provider List

This Belongs To:

1

Date:

2

Type of Medical Provider:	Name of Provider/Practice	Phone Number	Email	Why Do I See Them?
Ex: Specialist - Cardiologist	Ex: Dr. Smith	Ex: 555 - 555 - 5555	Ex: mydoctor@doctor.com	Ex: Takes care of my heart
Primary Doctor				
Primary Doctor				
Specialist Type:				
Specialist Type:				
Specialist Type:				
Specialist Type:				
Hospital				
Urgent Care				
Pharmacy				

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1 This Belongs To:

- Fill in your name or the name of the person this list is about.
- Add the date to know when the list was last updated.

2 About Your Medical Providers

- Fill in the information about your medical providers.
- If your provider doesn't have an email, do they use a patient portal for messaging?
- Ask for help if you don't know the information.

Reminder: It is important to review and update this information regularly.

