



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:

GETTING READY FOR A CHANGE

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: Getting Ready for a Change**.

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.





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 the transition to adult health care, with resources for more information and help.



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 Guide

This Side-By-Side Guide is to help you know that a change is coming. That change is called transition to adulthood and will impact many parts of your life. One area in particular is your health care. The guide will help you understand what transition means, and what health care transition means. It will help you start to think about your life as an adult and especially what your health care may be like.





What is Transition to Adulthood?

This is an exciting part of your life. You are growing and learning to do more things for yourself. You are starting to think more about your future and plan what your life will look like as you leave school and live life as an adult.



Before you know it, you are going to be an adult. You will soon move from going to school to life as an adult. This time in your life is called a transition. The word transition means a change or shift from one thing to another. It can mean:

- A change from being in school full time
- A change from being a child to becoming an adult
- A change from other people making decisions for you
- A change to making your own choices and decisions



Transition can mean changes in all the parts of your life:

- Changing from school to work
- Where you live and who you live with
- What you do in your free time
- Who you spend time with
- And more



That Is a Lot

That is a lot to think about and plan for. The good news is it does not need to happen all at once. Transition is a journey – it takes some time to plan, to learn what you need to know or do, and to get where you want to go.



LIFE DOMAINS

What Are the Life Domains?

As you become an adult you can start to be in charge of the different areas of your life. These life areas are called Life Domains.



Daily Life & Employment:

What you do as part of everyday life – school, work, volunteering, routines, family life.



Community Living:

Where you live, housing and living options, transportation, neighborhood and community



Safety & Security:

Legal rights, staying safe from injury or abuse, being ready for emergencies.



Social & Spirituality:

Friendships and personal relationships, leisure and recreation, faith and spiritual life.



Advocacy & Engagement:

Making life choices, speaking up for self and others, partnering for change.



Healthy Living:

Health care, healthy food, being physically active, planning for care and supports.



Understanding the Life Domains

There are a lot of changes to plan for. To get started, you can think about some of the questions listed below in each of the Life Domains.



Daily Life & Employment:

- Will I go to college or trade school?
- What kind of job would I like?



Community Living:

- Where will I live?
- Will I move out of my family home?



Safety & Security:

- How will I keep myself safe?
- What are my legal rights as an adult?



Social & Spirituality:

- How will I keep in touch with my friends or make new ones?
- What kind of faith life do I want, if any?



Advocacy & Engagement:

- How will I take charge of my life when I am an adult?
- How do I speak up for myself?



Healthy Living:

- What does healthy look like for me?
- What do I need to know about health and health care?

 **Living a Healthy Life**

Wellness & Self-Care: Fitness and physical activity, healthy food, healthy lifestyle choices.

 Health Care Transition

A close-up photograph of a medical history form. A silver stethoscope is resting on the form, with its chest piece positioned over the 'Family Physician and/or Nurse' section. A pair of glasses with orange frames is also visible in the upper left corner. The form includes sections for 'General Information' and 'Family Physician and/or Nurse'. The 'General Information' section has fields for 'Participant', 'Sex', 'Address', 'Contact phone numbers', 'Birth date', 'City', and 'Post'. The 'Family Physician and/or Nurse' section has fields for 'Name', 'Address', 'Phone', and 'Fax'. There are also checkboxes for 'May I send you my medical records?' and 'May I send you my insurance information?'. A pen is lying on the form near the bottom right.

- Moving from a doctor who sees children to a doctor who sees adults.
- Deciding things about your own health
- Learning about your rights and responsibilities around health care

When you are young, your parents or other responsible adults in your life take care of a lot of things for you. They help and decide things for you. They decide things about your health care. They take care of a lot of things for your health care.

When you are an adult, it may be very different. You may do many or all of your health care tasks and make health care decisions for yourself.



To learn more about different kinds of doctors and specialists, download the EZ-Reader: Getting Read For A Change: What Does That Mean? from the Toolkit Series.



Life Trajectory: Moving to Adult Health Care

 **Life Trajectory | Moving to Adult Health Care**

What are things that you think are going well with your health care now?

What are things that could be better or you would change?

Vision for What I Want

What are things that you like about your doctors and other health care people that you have now? What are the things you want to make sure you will still have in your adult health care workers?

What I Don't Want

What are things that you don't like about your doctors and the health care workers that you have now? What are the things you want to make sure are different in your adult health care?

 Charting the LifeCourse Framework and Tools
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When you are an adult, you will be choosing who you want to provide your health care. Thinking about your current doctors and health care workers will help you know what to look for in your adult health care workers.

This trajectory can help you think about:

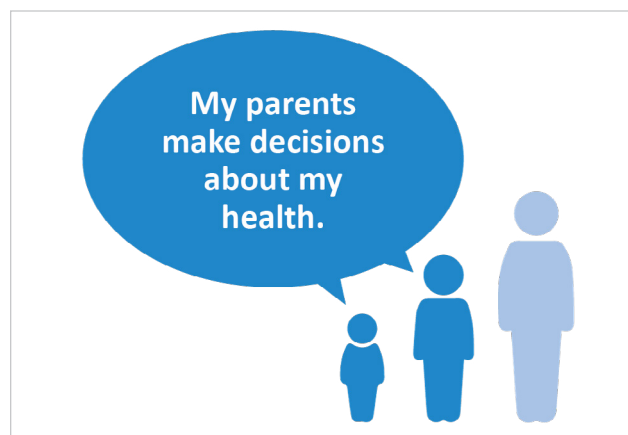
- What you like about your doctors
- What you don't like about your doctors
- What is working with your health care now and in the past

You can find and download the Life Trajectory: Moving to Adult Health Care and Tip Sheet in the resource section.

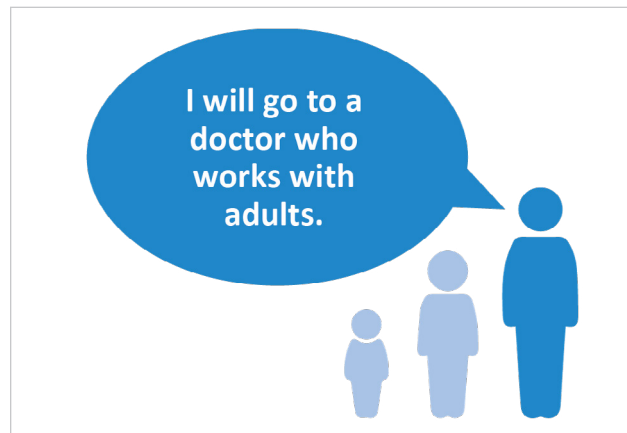




💡 My Health Care as a Child and Youth



💡 My Health Care as an Adult

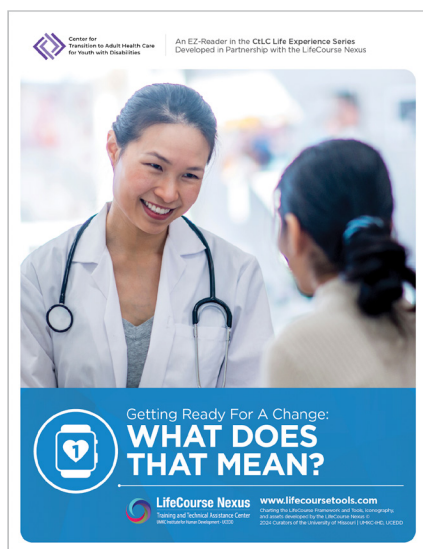


*Some youth go to doctors that see both children and adults. Even if you do not change to a new doctor, there will still be changes when you visit your doctor and the roles you play in your own health care.





► Learn. Talk. Do. For Supporters



Learn

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

Encourage them to read (or read with them) the EZ-Reader **Getting Ready For A Change: What Does That Mean?**, to learn more about health care transition and what may be different for them in adult health care.



To learn more about different kinds of doctors and specialists, download the EZ-Reader: *Getting Ready For A Change: What Does That Mean?* from the Toolkit Series.



Talk

The most important thing for the youth in this kit is to realize and understand that a change is coming. They should understand what health care transition means in general and globally. They will learn more about each specific aspect of health care transition in the next 5 kits.

Conversation Starters:

- Ask the youth to tell you in their own words what they think “transition” means.
- Use the Life Domains to talk about what their vision is for each domain – what kind of job they think would be interesting; do they want to go to college or technical school after they graduate; where they would like to live, etc. (see the domain related questions on the life domain table).
- Share with them what it was like for you to become an adult. What kind of choices you made; what you were worried about or excited about.
- Talk about health care tasks the youth does now. Discuss health care tasks they could do now or learn more about.



► Learn. Talk. Do. For Supporters

 Moving to Adult Health Care: Getting Ready for a Change

LIFE DOMAINS

Understanding the Life Domains
There are a lot of changes to plan for. To get started, you can think about some of the questions listed below in each of the Life Domains.

Daily Life & Employment:

- Will I go to college or trade school?
- What kind of job would I like?

Community Living:

- Where will I live?
- Will I move out of my family home?

Safety & Security:

- How will I keep myself safe?
- What are my legal rights as an adult?

Social & Spirituality:

- How will I keep in touch with my friends or make new ones?
- What kind of faith life do I want, if any?

Advocacy & Engagement:

- How will I take charge of my life when I am an adult?
- How do I speak up for myself?

Healthy Living:

- What does healthy look like for me?
- What do I need to know about health and health care?

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Do.

The **Understanding Life Domains** section on page 6 and the **Life Trajectory: Moving to Adult Health Care tool** shown on page 8, offer great opportunities to facilitate conversations. You might look for times that you can have the discussions (for example, in the car on the way home from a doctor's appointment), rather than sitting down to fill them out. The conversations can happen, and the information can be filled in, over time.

Also, you may want to reflect on your own vision as a supporter. What are things you notice that are going well with your self-advocate's doctors or health care workers? What are things not going well? Health care transition can impact the entire family and understanding each other's vision can help create a plan forward!



ADDITIONAL RESOURCES

► Resources

- Charting the LifeCourse Trajectory: Moving to Adult Health Care and Tip Sheet
<https://umkc.canto.com/b/LL38V>
- Got Transition Video: *What is Health Care Transition, HCT 101*
https://www.youtube.com/watch?v=7c_J8x_R-zM
- *Health Care Transition Timeline for Youth and Young Adults*
<https://gottransition.org/resource/?hct-timeline-youth-young-adults>
- Infographic — Which Got Transition Resources are for You?
<https://gottransition.org/resource/youth-families-infographic>
- Health Care Transition Quiz
<https://gottransition.org/youth-and-young-adults/hct-quiz.cfm>
- *5 Steps to Prepare for Health Care Transition*
<https://gottransition.org/resource/?five-steps-prepare-for-hct>
- Infographic — Moving to Adult Health Care
<https://gottransition.org/resource/?pediatric-vs-adult-care-differences>
- System Differences Between Pediatric and Adult Health Care
<https://gottransition.org/resource/?system-differences-between-pediatric-and-adult-health-care>



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

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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An EZ-Reader in the **CtLC Life Experience Series**
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Getting Ready For A Change:

WHAT DOES THAT MEAN?



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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, **Getting Ready for A Change: What Does That Mean?**, is to help you learn that a change is coming. You will soon be an adult. This booklet will help you learn about that change and what it means for your health care as an adult.



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.



When You Are Young



When you are young, you rely on your parents to take care of a lot of things.



They decide things for you and help you.



This is true about your health care.



Health Care When You Are Young



When you are a child, your parents take care of a lot of things around health care.



Parents schedule appointments with doctors and other specialists.



They pay for your health care.



What Do I Need to Know?



When you are a child, your parents make decisions about your health.



They might decide if you have surgery or take a certain medicine.



Your parents might talk to your doctor for you.



What Is Health Care Transition?



As you get older, you can start doing more things for yourself.



You can start to take charge of your own health care.



This is called health care transition.



What Does Transition Mean?



Transition is a word that means changing from one thing to another.



Health care transition means moving from childhood care to adult care.



This can look different based on your abilities.



What Do I Need to Know?



Managing your health and wellness is an important part of you becoming an adult.



It is a big step in living the life that you want.



As an adult you might do everything for your health, or just some things.



What Can I Do Now?



Now that you know a change is coming, you can do things to get ready.



Talk to your parents about ways you can do more health care tasks.



Ask questions about your health care at home and at medical appointments.



Resources

Got Transition - Health Care Transition Quiz

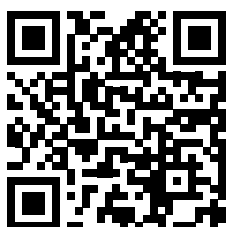
www.gottransition.org/youth-and-young-adults/hct-quiz.cfm

This is an online quiz that can help you to know if you are ready for health care transition. The quiz has questions about medication, doctors, and other health care topics.

Health Care Transition Readiness Assessment

www.gottransition.org/resource/index.cfm?tra-iep-english

This printable pdf will show you where you are in your health care transition journey. It will show you where you are on track, and where you need some work. You can check boxes and circle numbers to fill out this form.



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).***



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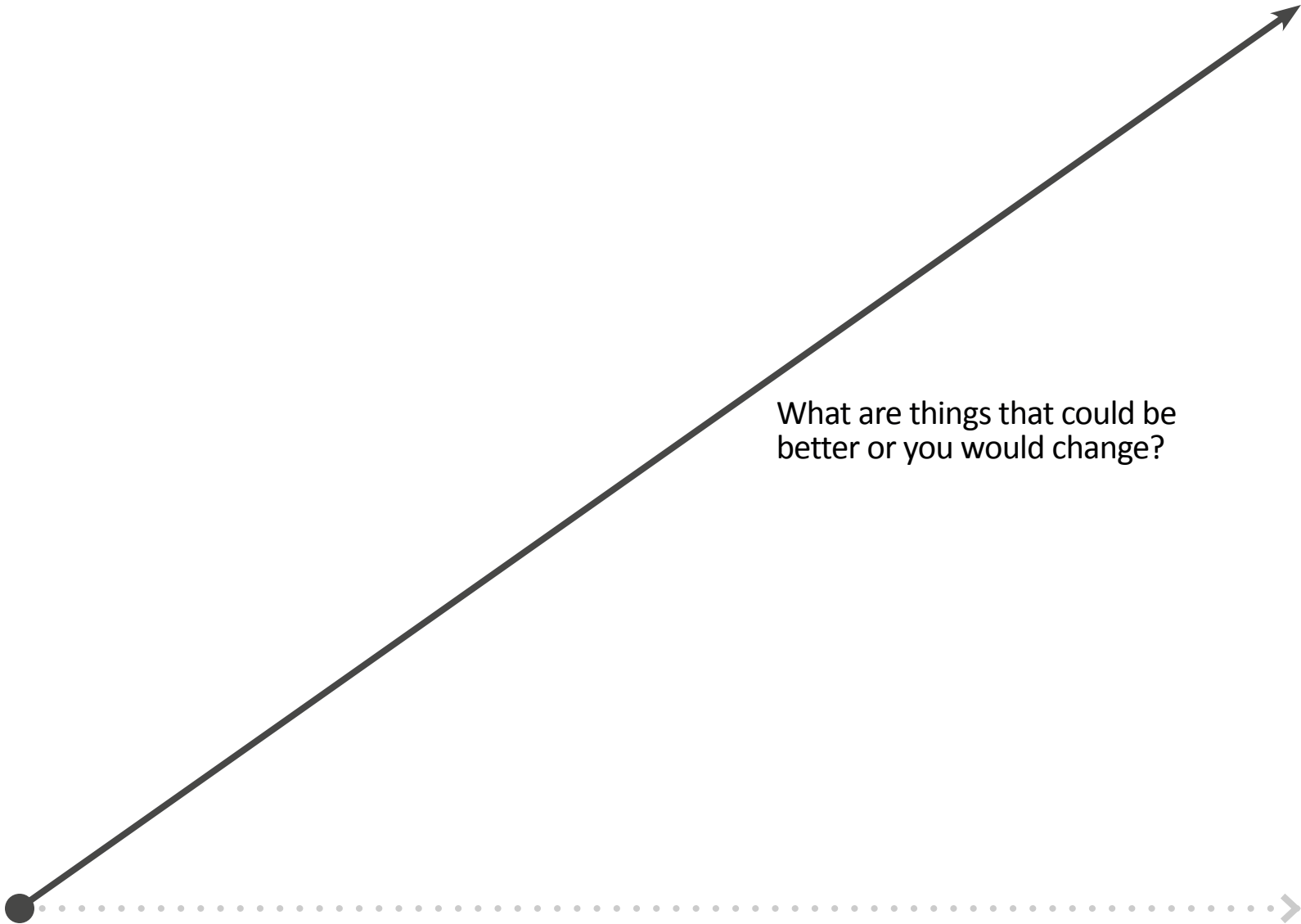
What are things that you think are going well with your health care now?

Vision for What I Want

What are things that you like about your doctors and other health care people that you have now? What are the things you want to make sure you will still have in your adult health care workers?

What I Don't Want

What are things that you don't like about your doctors and the health care workers that you have now? What are the things you want to make sure are different in your adult health care?





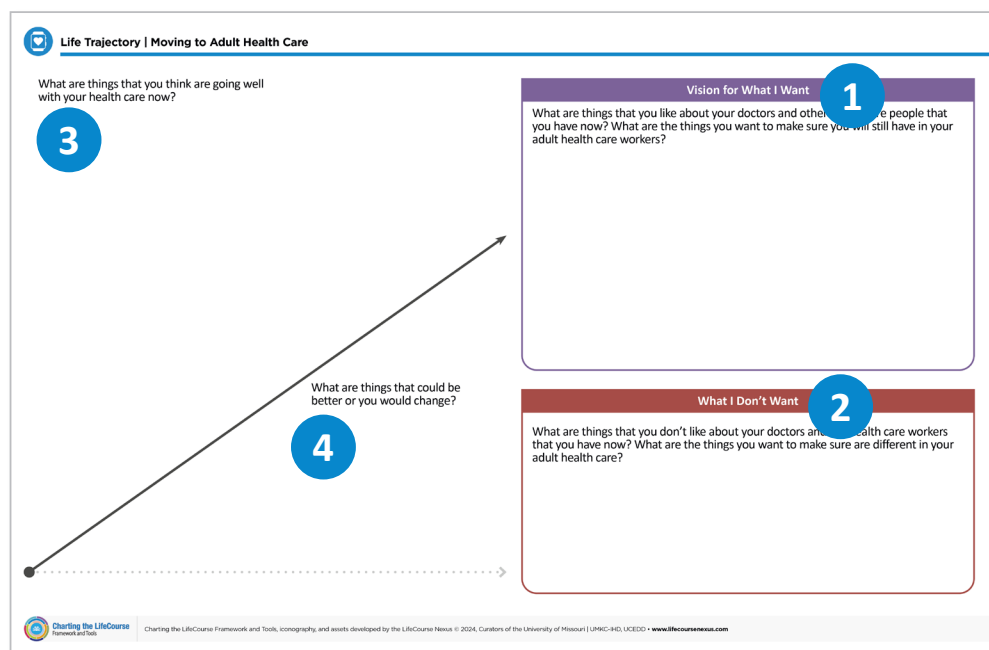
Overview

When you are an adult, you will be choosing who you want to provide your health care. Thinking about your current doctors and health care workers will help you know what to look for in your adult health care workers.

This trajectory can help you think about:

- what you like about your doctors
- what you don't like about your doctors
- what is working with your health care now and in the past

How To Use It



1 Vision for What I Want

- What do you like about your doctors or health care workers now?
For example, do you like...
 - How they listen to you?
 - How they talk to you in a way that helps you understand?
 - How easy it is for you to visit them?

2 What I Don't Want

- What do not like about your doctors or health care workers now?
For example, do you not like...
 - Waiting for a long time?
 - How they seem rushed?
 - How they make you feel unheard?

3 Above the Trajectory

- What is good about your health care now?
For example,
 - Do you go to appointments regularly?
 - Are your medications helping you?
 - Do you feel healthy?

4 Below the Trajectory

- What are things that could be better?
For example,
 - Are you missing appointments?
 - Are you not taking your medication?
 - Do you not feel good?