



Charting the LifeCourse
Framework and Tools

Charting the LifeCourse – Health Care Transition

RAISE Summit

July 25, 2024

www.lifecoursetools.com

About Marie

Wife, Daughter, Caregiver, Dog Mom

LifeCourse Nexus

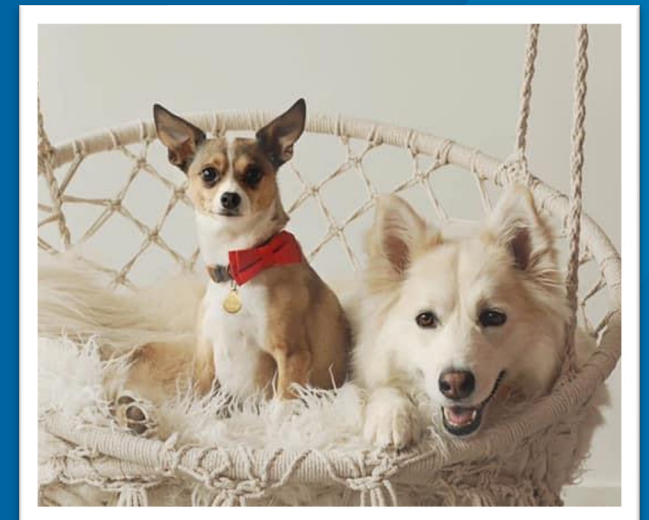
- Institute of Human Development, UCEDD
- University of Kansas City-Missouri (UMKC)

Background

- Occupational therapy
- Applied behavior science

Hobbies

- Traveling
- Yoga
- Exploring new restaurants
- Going to concerts



Objectives

- Describe Charting the LifeCourse
- List examples of Healthy Living
- Identify resources to support health care transition for youth and young adults

What is Charting the LifeCourse?

Created for people and families of all abilities and all ages to:

- **Explore** life possibilities and discover options
- **Problem** solve to find solutions and identify resources
- **Plan** goals and action steps for now and the future
- Advocate and navigate for a vision
- Access a variety of integrated supports

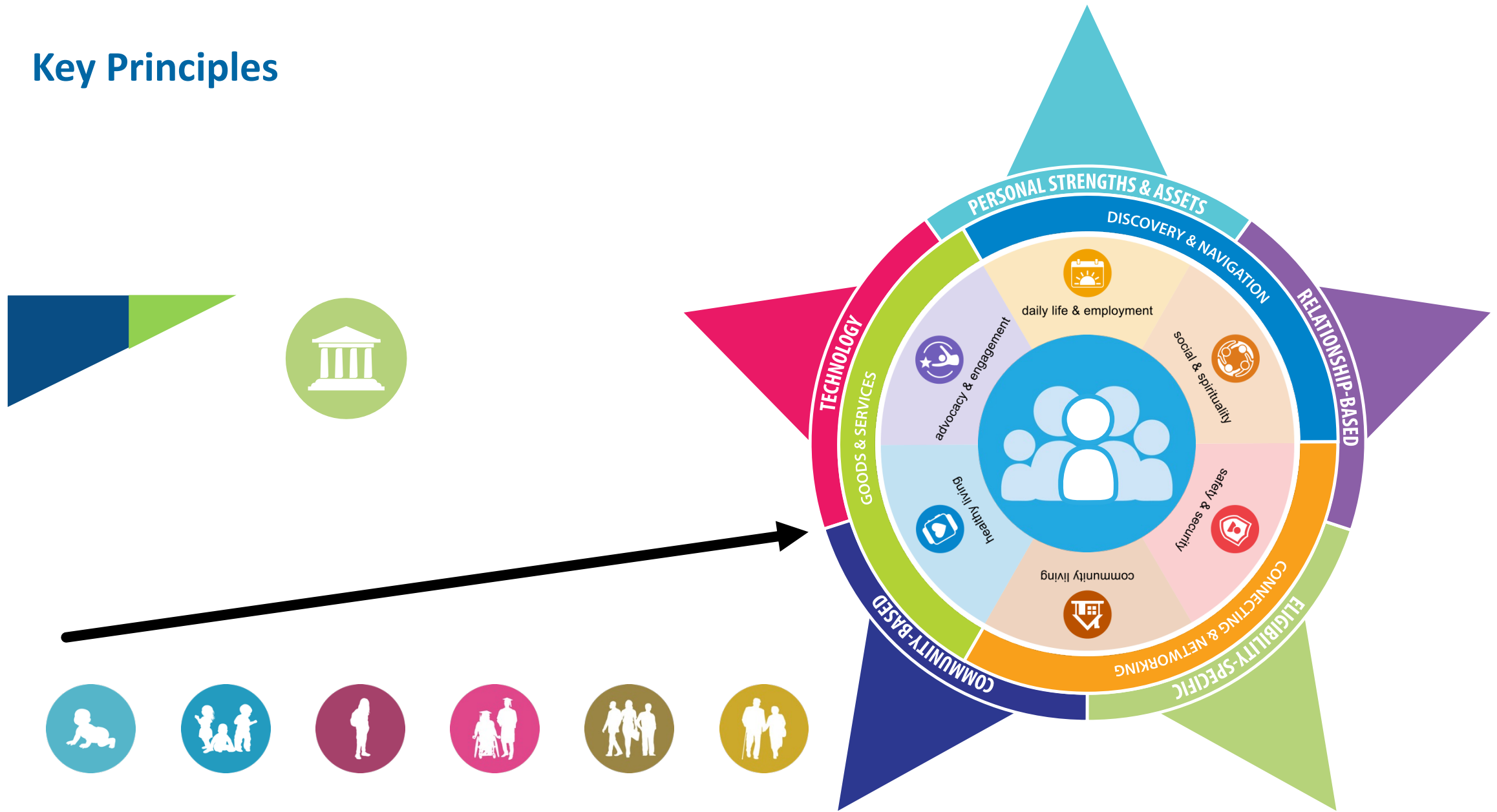




All people have the right to live, love, work, play and pursue their life aspirations in their community.

CHARTING THE LIFECOURSE FRAMEWORK | CORE BELIEF

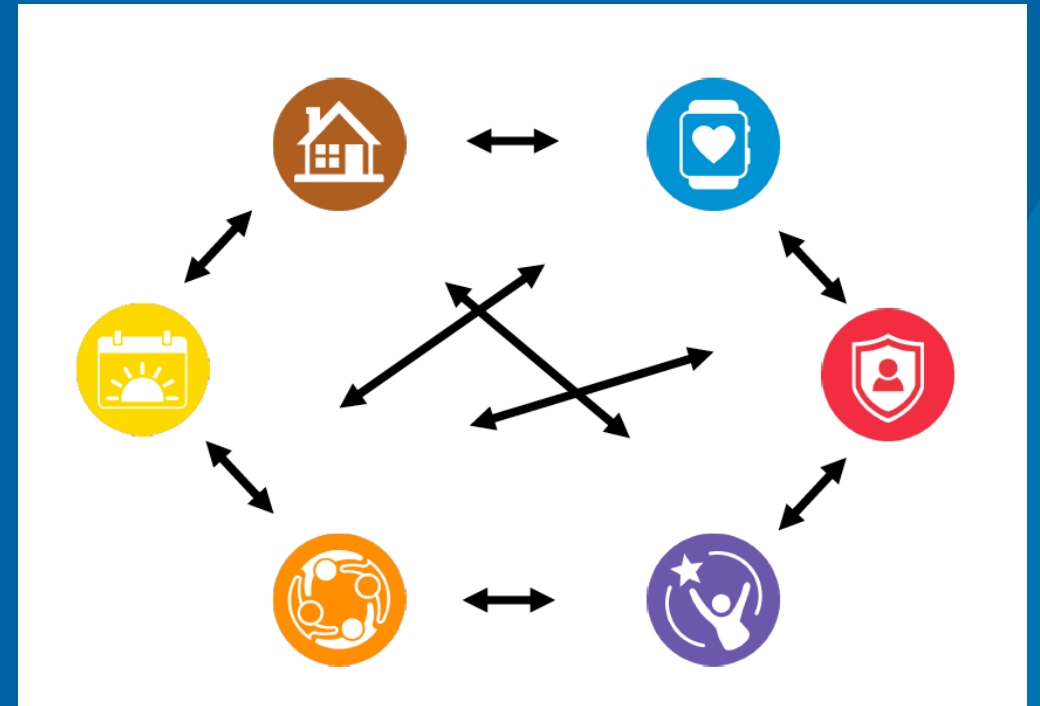
Key Principles



Why Focus on Healthy Living?

All Connected and Integrated

- Health can impact all the other domains and vice versa
- What happens early in life can affect adult life and as we age
- We don't normally "plan" for our health
- Navigating environmental and public health issues



What is Healthy Living?

Life Domain

- Managing and assessing health care
 - Medical, mental, and behavioral health
- Sexual and reproductive health
- Long-term health needs
- Wellness, fitness, nutrition, and self-care



Wellness & Self-Care

Sub-Domain

- Preventative care and lifestyle Choices



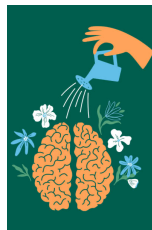
- Fitness and physical activity



- Healthy meals and snacks



- Managing stress and mental health



Comprehensive Healthcare

Sub-Domain

- Primary care and specialty care
- Manage chronic conditions/disability



- Vision, hearing, dental care



- Coordinate health care needs, services, costs, insurance, and benefits



Long-Term Supports

Sub-Domain

- Support activities of daily living



- Nursing and specialty care



- Home and community-based services



- Planning and navigating resources and options



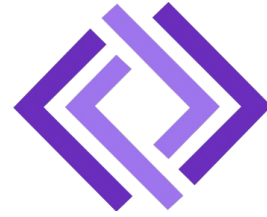
Health Care Transition

New Toolkits



www.lifecoursetools.com

Project Partners



Center for
Transition to Adult Health Care
for Youth with Disabilities



LifeCourse Nexus

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

Development Process

SPAN Parent Advocacy Network

- Youth advisors
- Content feedback

Nationwide Feedback Group

- 8 youth/young adults
- 7 family members
- Toolkit feedback

What's a toolkit?

**Target Audience:
Youth with I/DD**

Each kit has a topic.

1. Getting Ready for a Change
2. Knowing About Your Health
3. Day-to-Day Healthy Living Routines
4. Health Care Visits and Interactions
5. Understanding your Legal Rights in Health Care
6. Making the Move to Adult Care

What's a toolkit?

Target Audience:
Youth with I/DD

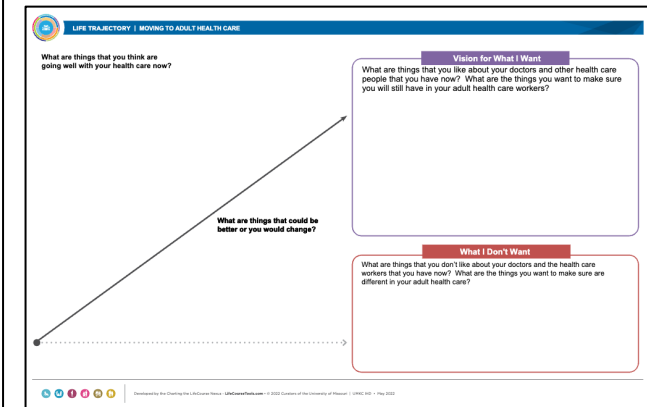
A toolkit includes...



Side-By-Side Guide






EZ-Reader



Tool

What's a Side-by-Side Guide?



- Goals
 - Learn 
 - Talk 
 - Do 
- Supporter Tips
 - ▶ **Learn. Talk. Do. For Supporters**
- Resources

What's an EZ-Reader?



- Learn more about a specific topic
- Can stand alone
- Uses words and pictures
 - Short sentences
- Resources



What's a tool?

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?

Developed by the Charting the LifeCourse Nexus - LifeCourseTools.com • © 2022 Curators of the University of Missouri | UMHC 100 • May 2022

- Action/To-Do
- Worksheet



Charting the LifeCourse
Framework and Tools

Toolkit 1 – Getting Ready for A Change

www.lifecoursetools.com



Moving to Adult Health Care: GETTING READY FOR A CHANGE

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

www.lifecoursetools.com
Charting the LifeCourse Framework and Tools, iconography, and assets developed by the LifeCourse Nexus
© 2024 Curators of the University of Missouri | UMKC-IHD, UCEDD



Moving to Adult Health Care: Getting Ready for a Change

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 (insert project website)

Toolkit Series

1. Getting Ready for a Change
2. Knowing About Your Health
3. Day-to-Day Health Routines
4. Leading Health Care Visits
5. Legal Rights and Decision Making
6. Making the Move

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.

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.



Moving to Adult Health Care: Getting Ready for a Change

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/healthyliving.

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" 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.





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 **Moving to Adult Health Care: What Does That Mean?**, to learn more about health care transition and what may be different for them in adult health care.



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



Talk

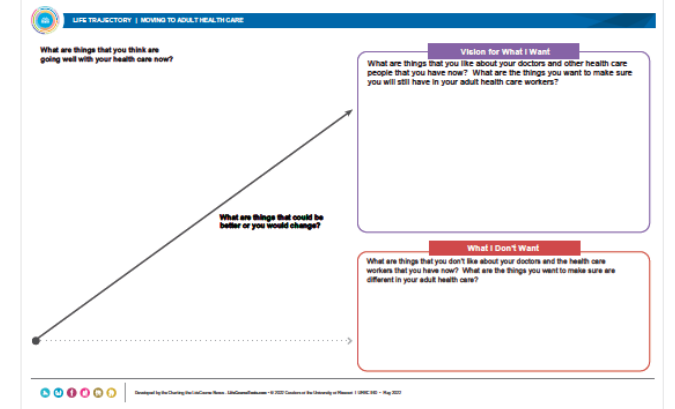
The most important thing for the youth in this kit is to realize and understand that a change is coming. They should understand what health care transition means in general and globally. They will learn more about each specific aspect of health care transition in the next 5 kits.

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



Do.

Help the youth complete the tool LifeCourse Trajectory: Moving to Adult Health Care.

Have conversations about each of the prompts, filling in information as the discussion proceeds. 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 out the tool. The conversations can happen, and the tool can be completed, over time.





Moving to Adult Health Care: **WHAT DOES THAT MEAN?**



LifeCourse Nexus
Training and Technical Assistance Center
UMKC Institute for Human Development - UCEDD

www.lifecoursetools.com

Charting the LifeCourse Framework and Tools, iconography,
and assets developed by the LifeCourse Nexus
© 2024 Curators of the University of Missouri | UMKC-IHD, UCEDD



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.



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 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?





Vision of What I Want

- Active
- Healthy and Fit/physically strong
- Healthy weight
- Access to fresh food – vegetables, fruit, etc
- Healthy enough to live, work, play where he wants
- Play basketball/workout

Vision of What I Don't Want

- Diabetes/Heart disease/serious issues
- Sedentary/inactive lifestyle
- Unhealthy weight
- Hospital stays/surgeries
- Out of control seizures
- Nursing home/institution

Ben's Vision for Healthy Living



Charting the LifeCourse
Framework and Tools

Kit 2 – Knowing About Your Health

www.lifecoursetools.com



Moving to Adult Healthcare: KNOWING ABOUT YOUR HEALTH



Moving to Adult Health Care: Knowing About Your Health

KNOWING ABOUT YOUR HEALTH

Why Learn About This?



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

- Your parents or family knows all the details about any health issues you have.
- They know the names of your disabilities and how it affects you.
- They know about any treatments or surgeries you have had as a child.
- They 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.
- Know why you see each one.
- Know how to contact your doctors and other health workers.
- Know how to contact your therapists.
- Know the names of all your medications and why you take them.
- Know how much and how often you take each of your medications.

That's 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 don't 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.



Moving to Adult Health Care: Knowing About Your Health

FOR SUPPORTERS

Learn. Talk. Do. For Supporters



Learn

Read through the guide and EZ Reader with the youth. If there are things they don't understand, try explaining it using different words or in smaller bites. Use real life details to illustrate points. Stop and share stories or details as you go.

Answer any questions they might have as you go. Use real life details to illustrate points. Stop and share stories or details as you go. Answer any questions they might have as you go.



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?





Moving to Adult Health Care:

DIFFERENT KINDS OF DOCTORS & SPECIALISTS



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.



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.





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:				








Charting the LifeCourse Framework and Tools, iconography, and assets developed by the LifeCourse Nexus
 © 2023 Curators of the University of Missouri | UMKC IHD, UCEDD • www.lifecoursetools.com



Healthy Living | Medical Provider List

This Medical Provider List Belongs To: _____

 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, iconography, and assets developed by the LifeCourse Nexus
 © 2023 Curators of the University of Missouri | UMKC IHD, UCEDD • www.lifecoursetools.com





Charting the LifeCourse
Framework and Tools

Kit 3 – Day-to-Day Healthy Living Routines

In Development

www.lifecoursetools.com

Kit 3

Side-by-Side Guide

- Having regular checkups with doctors, dentist, eye doctor, etc.
- Taking medications
- Eating healthy
- Staying active
- Prioritizing overall wellness, including mental health

EZ-Reader

- Managing medication



Healthy Living | Medication List

This Medication List Belongs To: _____

I Take This Medication:	How Much I Take:	Time of Day I Take This Medication:				Why I Take This Medication?	I Started Taking This Medication On:	I Stop Taking This Medication On:	I Was Told to Take This Medication By:
		Morning	Afternoon	Evening	Bedtime				
Ex: Aspirin	Ex: 81 mg	✓		✓		Ex: My Heart	Ex: February 4, 2023	Ex: March 24, 2024	Ex: Dr. Smith



Charting the LifeCourse Framework and Tools, iconography, and assets developed by the LifeCourse Nexus © 2023 Curators of the University of Missouri | UMKC IHD, UCEDD • www.lifecoursetools.com





Past Life Experiences

List things in the past that helped me be healthy and make good choices about my health

Moving Forward

List what needs to happen to improve my health, make healthy choices, and support my vision for a healthy life

List things in the past that caused me to be unhealthy or make poor choices about my health

List things that might make it hard to reach my healthy living goals or make healthy choices

Vision for Healthy Living

What do I want my healthy good life to look like?

My vision for a good life

What health issues am I having or am I worried about?

Are there diagnosis or disability specific concerns?

What is my vision around fitness, nutrition and wellness?

What I Don't Want

What are things I don't want to happen with my health?

What I don't want in my life





Charting the LifeCourse
Framework and Tools

Kit 4 – Health Care Visits and Interactions

In Development

www.lifecoursetools.com

Kit 4

Side-by-Side Guide

- Communicating with health care workers
- Advocating to health care workers on how to best support during visit
- Leading interactions

EZ-Reader

- Getting ready for a health care visit – before, during, after



Healthy Living | Today's Health Care Visit

FILL OUT THIS PAGE BEFORE GOING TO THE VISIT

My Name: _____

Supporter (if needed): _____

ABOUT MY APPOINTMENT

Date of Appointment _____ Who is with me today? _____

Appointment Type (check one): Family Doctor Specialist (specify what kind) _____

Eye Dentist Other(x-ray, therapy, lab) Walk-In Clinic Urgent Care Hospital/ER Visit

THINGS TO BRING WITH ME

My ID Medication List Health Insurance Card Medicaid/Medicare Card Way of Payment

Other: _____ Other: _____ Other: _____

WHY AM I AT THE DOCTOR OR HEALTH CARE PROVIDER TODAY?

Feeling Sick Injured/Hurt Regular Checkup/Physical Medication Refill/Change

HAVE ANY OF THESE THINGS BEEN BOTHERING ME IN THE LAST WEEK OR LONGER? (check if yes)

Pain Head Throat Skin

Falls/Dizziness Eyes Heart Arm/Hands

Sleeping Ears Breathing Leg/Feet

No Energy/Tired Nose Stomach Medication

Emotions/Feelings Mouth/Throat Going to Bathroom Sexual Health

DESCRIBE WHAT IS GOING ON:

Have I been seen for this reason before? Yes/No

QUESTIONS I WANT TO ASK TODAY:



Charting the LifeCourse
Framework and Tools

Charting the LifeCourse Framework and Tools, iconography, and assets developed by the LifeCourse Nexus
© 2024 Curators of the University of Missouri | UMKC-IHD, UCEDD • www.lifecoursetools.com



Healthy Living | Today's Health Care Visit

FILL OUT THIS PAGE DURING OR AFTER THE VISIT

WHAT DID WE TALK ABOUT AND DO?

NEXT STEPS

Things I need like: tests, exams, X-rays or bloodwork; follow-up visits with this doctor; appointments with a different doctor or health care worker, ways I can be healthier at home.

MEDICATIONS: WERE THERE ANY CHANGES TO MY MEDICATION? YES NO

Fill out for my new medication(s):

My New Medication:	How Much I Take:	Time of Day I Take This Medication:				Why I Take This Medication?	I Start Taking This Medication On:	I Stop Taking This Medication On:	I Was Told to Take This Medication By:
Ex: Aspirin	Ex: 81 mg	Morning	Afternoon	Evening	Bedtime	Ex: My Heart	Ex: Feb 4, 2023	Ex: Mar 24, 2024	Ex: Dr. Smith
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				

List medications I should stop taking, or other things I should know about my medications:



Charting the LifeCourse
Framework and Tools

Charting the LifeCourse Framework and Tools, iconography, and assets developed by the LifeCourse Nexus
© 2024 Curators of the University of Missouri | UMKC-IHD, UCEDD • www.lifecoursetools.com





Charting the LifeCourse
Framework and Tools

Kit 5 - Understanding Legal Rights in Health and Health Care

In Development

www.lifecoursetools.com

Kit 5

Side-by-Side Guide

- Legal rights around health care based on legal decision-making status
- Privacy, access to records, parental access
- Decision-making around procedures, surgeries, taking medications, etc.

EZ-Reader

- Supported Decision Making

Exploring Decision-Making Supports for Health

- Taken from a more comprehensive tool that covers all domains
- Every question may not apply
- Can add other questions relevant to the individual and their needs



Charting the LifeCourse | 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 discussion with family, friends and other supporters.

Name of Individual: _____

Name of person completing this form: _____

Relationship to individual (circle one): Self Family Friend Guardian Other: _____

How long have you known the individual? _____

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, seizure, 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 what could happen if I refuse medical treatment?			
Can I alert others and seek medical help for/during 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 domains, is available at <https://www.lifecoursetools.com/lifecourse-library/exploring-the-life-domains/supported-decision-making/>



Charting the LifeCourse Framework and Tools, Iconography, and assets developed by the LifeCourse Nexus © 2023 Curators of the University of Missouri | UMKC IHD, UCEDD • www.lifecoursetools.com



Charting the LifeCourse
Framework and Tools

Kit 6 - Making the Move to Adult Care

In Development

www.lifecoursetools.com

Kit 6

Side-by-Side Guide

- Finding adult providers
- Making informed decisions around choosing adult health care professionals
- Getting ready for appts with new adult providers– making list of questions, organizing info, setting up reminders
- Staying insured as an adult

EZ-Reader

- Health insurance

Center for Transition to Adult Health Care



Center for
Transition to Adult Health Care
for Youth with Disabilities



About Us

Resources

Data



<https://movingtoadulthealthcare.org/>





Exploring the Life Domains

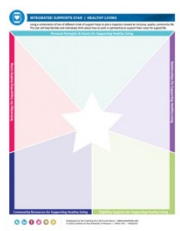
Healthy Living

Managing and accessing health care and staying well – medical, mental health, behavioral health, developmental, wellness, and nutrition.



Health is connected closely to many other life domains. If you aren't healthy, you might not be able to have the job you want or be able to live where you would like. You might not be able to spend time with family and friends or be involved in the community and other desired activities. Planning for and looking after one's health and wellness can be an important factor in living the kind of life that you want. Making sure you get proper medical care, paying attention to nutrition and fitness, and looking after your mental health are all part of healthy living.

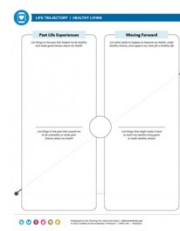
Getting Started



Integrated Support Star for Healthy Living

The Healthy Living Integrated Supports Star helps you explore supports that can help you reach your goals for living a healthy life.

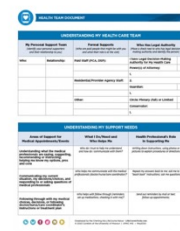
[Download Tool](#)



Trajectory for Healthy Living

Develop a vision for a healthy life, consider past experiences that helped or not, and plan steps for being healthy and well.

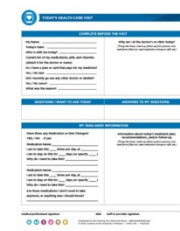
[Download Tool](#)



My Health Care Team and Support Needs

Map your health care support team and how you can best be supported when working with health care professionals and accessing care.

[Download Tool](#)



Today's Health Care Visit

Keep track of everything you want to share or ask about, as well as remember what happened during a health care visit, with this tool.

[Download Tool](#)

Questions or Reflections?



www.lifecoursetools.com

THANK YOU!

Marie Clark

marieclark@umkc.edu

www.lifecoursetools.com

