

# All About Me

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A guide to  
taking charge of  
your health care

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**Children's Mercy**  
KANSAS CITY





## A NOTE FROM THE CHILDREN'S MERCY TEEN ADVISORY BOARD

As much as we would like to, we can't be patients at Children's Mercy forever. We are all growing up, getting older, our bodies are changing and some diseases may move into different stages. There comes a time when we have to move on to different doctors and treatments; we need to prepare for transition into adult medical care. This information can also help your future doctors by providing them with information that will help make life-changing treatment plans. Being firm and knowledgeable about your needs is important.

There may be other times such as on vacation with your family, visiting relatives out of the state or country, traveling with school or even going to college where you might need this information. Look at this information as your ticket to travel, be yourself and go anywhere you want to go. Whether you have a small problem or even a very serious problem, with this information you can go just about anywhere and be cared for. The more information you give doctors who don't know your history, the more aware they will be of you and your diagnosis and the better they can treat you.

Doctors will need to know about all surgeries and procedures you have had. They will need to know what meds you have and are currently taking. They also need information on your symptoms, like what triggers them and which strategies work best for you. The more details you provide, the better care you will receive in the future. Keep careful records and ask lots of questions. Remember this information is **ALL ABOUT YOU!**

Courtesy of Teen Advisory Board 2016





# TRANSITION TO ADULTHOOD

As you get older, Children's Mercy will help you prepare for adulthood, including transferring your medical care to a doctor who cares for adults. Most patients can learn to take care of their own health. It takes help from your medical team and support from the important people in your life.

## WHAT DOES THIS MEAN FOR YOU?

- Around age 12, we will start talking with you about learning to take care of your own health care.
- By age 15, we want you to spend part of your clinic visit talking alone with your medical team.
- At age 18, our goal is for you to be fully involved in your own health care.
- By age 18-21, you will receive help to transition your care to a doctor outside of Children's Mercy who takes care of adults.
- The process may be a little different if you have special health care needs or an intellectual disability.

## TEEN AND FAMILY ADVISORY BOARDS

Members of our Teen and Family Advisory Boards have helped us decide what information will be most helpful to teens and their families.

## PLANNING FOR TRANSITION

You and your medical team will create a plan just for you. We will teach you about your health care needs and give you information on other topics, such as finding a new doctor, planning for employment and advocating for yourself. We have identified the steps to help you start to manage your own health and tips to learn those skills.

## RESOURCES

We have information available on a variety of topics to help you with this transition process. Our goal is for you to leave Children's Mercy with the skills you need to take control of medical and personal decisions.





## TRANSITION TIMELINE

# THE PATH TO TAKING CARE OF YOUR HEALTH

Learning to take care of your medical needs on your own can be overwhelming. Below is a list of tasks you should be doing at different ages to help guide you on your path to transition.

### AGE 12-14

- Learn name of medical problem/diagnosis.
- Learn health insurance plan you have.
- List medications and why you take them.
- Know when to take medications.
- Learn about any allergies you have.
- Create your 3-Sentence Summary.
- Create a MyHealth Passport.
- At age 13, begin using the MyChildrensMercy Patient Portal.
- Answer questions your doctors/nurses ask.
- Ask questions of your doctor/nurses.
- Tell someone when you are sick and need to see the doctor.
- Tell others how they can help you when you need them to.
- Know two people to call in case of an emergency.
- Know who to talk to if you need any help at school.
- Become involved in your individualized education program (IEP) or 504 plan, if you have one.





## AGE 15-17



- Become independent in taking medications.
- Refill pill box independently.
- Begin making lists of questions to ask your doctors during appointments.
- Start meeting with your doctor alone for part of your appointment.
- Keep a list of your medical problems and allergies.
- Keep your 3-Sentence Summary updated.
- Keep your MyHealth Passport updated.
- Assist in calling in medication refills—listen on speakerphone.
- Assist in making your own medical appointments—listen on speakerphone.
- Assist in calling medical team if you have any questions or changes in your health—listen on speakerphone.
- Learn how to contact insurance company for questions/concerns.
- Understand how your insurance may change when you turn 18 or 19 and what your new plan may look like.
- Begin discussing future school or career goals.
- Actively participate in IEP or 504 plan, if you have one.
- Learn about your legal rights when you turn 18.
- Understand how drugs, alcohol, or cigarettes could affect your health.
- Understand the effects your medical condition may have on your sexual/reproductive life.

## AGE 18-21



- Take medications without assistance.
- Order medication refills without assistance.
- Make medical appointments on your own.
- Independently arrange for transportation/drive to your medical appointments.
- Keep your 3-Sentence Summary updated.
- Keep your MyHealth Passport updated.
- Be able to know what an emergency is for your health condition.
- Call your medical team independently if you have any changes in your health.
- Become familiar with employment support resources: Vocational Rehabilitation, access offices at school, career centers.
- Make a plan for college/training.
- Contact your insurance company for questions/concerns independently.
- Continue to learn how your insurance may have changed at age 18 or 19.
- Understand how drugs, alcohol, or cigarettes could affect your health.
- Understand the effects your medical condition may have on your sexual/reproductive life.
- Understand at what age you will transition to an adult health care provider
- Ask your health care team and family which adult health care providers would be good choices to transition your care.



# 3-SENTENCE SUMMARY

## WHAT IS A 3-SENTENCE SUMMARY?

The 3-Sentence Summary provides some tips on how to describe your health and current needs in about three sentences. This skill is really important when you meet your new adult health care providers or when you don't get to spend too much time with a health care provider. After you give your summary, your provider will typically have questions. This doesn't mean you've forgotten important information, it just means you've given enough information that they can now focus on what's important to you during the appointment.

## HOW DO I USE IT?

Sentence 1: My age, diagnosis and brief medical history

Sentence 2: My treatment plan

Sentence 3: My question/concern to talk about during the visit

## EXAMPLE

"Hi, my name is Sally Butamol.

1. I am 16 and have asthma. I have been hospitalized twice, but not in the past 5 years.
2. I have been taking Ventolin and Flovent since I was 3.
3. I am here today because I can't run anymore. I wheeze too much and can't breathe."

## NOW IT'S YOUR TURN:

- Practice with the health care providers you see the most.
- Ask if your 3-Sentence Summary is correct and includes all the important information.

Sentence 1: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Sentence 2: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Sentence 3: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_





# MYHEALTH PASSPORT

## WHAT IS A MYHEALTH PASSPORT?

- Personalized wallet-size card where you can keep all your medical information. Take a picture of it and save it on your phone.
- Useful when you go to a new doctor, complete a health form or visit an emergency room.
- Created by you online—it's free!

## HOW DO I GET ONE?

- Go to [sickkids.ca/myhealthpassport](https://sickkids.ca/myhealthpassport).
- Choose your condition from the dropdown menu or choose generic.
- Fill in your medical and contact information.
- You can ask your health care provider for help.

## WHAT INFORMATION WILL I NEED TO COMPLETE MYHEALTH PASSPORT?

- Names of your conditions
- Names of your medications
- Names and dates of any major procedures or operations
- Immunization history
- Any special health care needs, allergies, mobility aids
- Names and phone numbers of your health care providers and emergency contacts

Used with permission from the Hospital for Sick Children, Toronto, Ontario, Canada: [sickkids.ca](https://sickkids.ca)



## MYHEALTH PASSPORT TOOL

This is the generic example of the MyHealth Passport tool that you can fill out online at [sickkids.ca/myhealthpassport](http://sickkids.ca/myhealthpassport). There are over 70 diagnosis specific options from which to choose. After you fill it out, print out the wallet-size card with all of the information. You can take a picture with your phone and keep it with you.

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Name

Date of birth

Do you have a medical problem? What is it called and when was it diagnosed?

Immunizations

DTP  MMR  HIB  Varicella  Meningitis

Pneumovax  Prevnar HPV  Hepatitis A  Hepatitis B

Other immunizations

Have you had any operations? What for and when?

Are you on any medications—consider including contraceptive pills, patches, IUCDs. If not comfortable with this, write “Ask me about my other medications.”

Drug allergies

Other allergies

Bone status

Blood group  A+  A-  B+  B-  O+  O-  AB+  AB-

People have different ways of paying for their health care or medications. Some examples are OHIP, Trillium, NHS, ODB, Kaiser, Blue Cross, Medicare, Medicaid. How do you pay for medications and health care?

What is your regular exercise routine?

Pediatric provider name and phone number

Primary care provider and number

Name and phone number of usual pharmacy (drugstore, chemist)

Special needs

Other information

Who should be called in case of emergency? Enter name and phone number.





# TAKING ON NEW ROLES IN YOUR HEALTH CARE

## BUILDING YOUR PARENT OR CAREGIVERS' TRUST

As you are becoming more independent in your medical care, you will be taking on some responsibilities your parents or caregivers usually take care of. It can be hard for them to give up the control of some of these things and you may need to work together to show you are responsible and trustworthy enough to take on these new roles.

Here are some tips on building your parents' or caregivers' trust:

**COMMUNICATE**—Open communication about your feelings, your wishes and your concerns are very important in building your parents' or caregivers' trust. You and your parents or caregivers may have different ideas on how to handle your care, but it's best to talk and find a plan that works for both of you.

**MAKE A PLAN FOR SUCCESS**—Write down your goals for taking on new responsibilities and make a plan to reach these goals. Decide what you will do if you find it is difficult to reach your goals, how to tell someone if you need help and who may be able to help you.

**FOLLOW THROUGH**—When you are given a task by your parents or caregivers, whether it's about your medical care or something else like a chore around the house, make sure you do what is asked of you. The more you show you can do it, the more they will trust you to do it on your own.

**BE RESPECTFUL AND TRUTHFUL**—It is important to always be respectful and tell the truth to your parents or caregivers. This is a great way to build trust. Even if you've done something wrong or have not followed through on a plan you made, it is better to be honest and tell your parents or caregivers than to try and hide it.

**BE PREPARED FOR CHALLENGES**—Building trust takes time! Remember that your parents or caregivers only want the best for you and they may have a hard time letting go of some of the things they do to help take care of you. Be patient and continue to share your feelings about this process with them.





# GOAL SETTING WITH YOUR MEDICAL TEAM

During your clinic visits, you and your health care team will be talking about different goals to help you take care of your health needs on your own. Your health care team will be there to help you, but it is up to you and your family to work on these goals between clinics so you can be ready when it is time for you to move to adult health care.

Some of the topics you may discuss are:

**MANAGING MY OWN HEALTH:** Ways to take on more responsibilities with your health. These goals may include taking your medications on your own, refilling your medications, as well as knowing your health information and how to share it with others.

**UNDERSTANDING MY MEDICAL CONDITION:** Learning your medical history and medical conditions and how these conditions may affect other parts of your life.

**MOVING TO AN ADULT DOCTOR:** If you are within a year of moving to an adult doctor, you will talk about goals to find a new doctor that works best for you. You will also talk about the best way to get your health information to the new doctor.



## GOALS YOU AND YOUR HEALTH CARE TEAM WILL CHOOSE FROM DURING YOUR CLINIC VISITS:

**3-SENTENCE SUMMARY** – create to describe your medical problems to review with your providers.

**MEDICAL HISTORY AND CONDITION** – be able to describe your medical condition and care you have needed.

**MEDICATIONS** – provide a list to any outside providers, school nurse and college campus health clinic.

**ALCOHOL, DRUGS AND TOBACCO** – explain how these could affect your medical problem.

**EMERGENCY CARE AND ASKING FOR HELP** – knowing when to ask for help when you have medical problems.

**CONTACT INFORMATION/INSURANCE** – keep insurance card and list of medical providers in phone/wallet

**MYHEALTH PASSPORT** – create and keep a copy in your wallet or copy it to your cell phone.

**PATIENT PORTAL** – enroll in and explore.

**GUARDIANSHIP OPTIONS** – work with agencies and a lawyer to establish limited or full guardianship at age 18.

**ADULT PROVIDER** – work with team to find and contact a new adult provider.

The transition timeline at the beginning of this book lists some other things to be working on in addition to the goals you set with your health care team.

## TIPS FOR SETTING GOALS

On the next page, there is a chart for you to track your goals to help you be more independent in taking care of your health. As you work with your health care team and parents/caregivers, be thinking about the following:

My health care goal is: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

What information do I need to reach my goals?:  
\_\_\_\_\_  
\_\_\_\_\_

Things I will need to do to reach my goals:  
\_\_\_\_\_  
\_\_\_\_\_

Problems I may have when trying to reach my goals or things that may make it difficult for me to reach my goals:  
\_\_\_\_\_  
\_\_\_\_\_

In order to succeed, I am going to ask for help from the following people:  
\_\_\_\_\_  
\_\_\_\_\_

What can I begin doing tomorrow to work toward my goals?:  
\_\_\_\_\_  
\_\_\_\_\_



# GOAL TRACKING SHEET

DATE	GOAL	WHAT DO I NEED	WHO CAN I ASK FOR HELP	I WOULD LIKE TO COMPLETE THIS GOAL BY	DATE COMPLETED
Example 3/15/15	Learn to take my medications without reminders from my parents	a. Set an alarm on my phone for when I need to take my medications  b. Keep my medications in the same place so I can always find them (kitchen cabinet )	Mom Dad	5/15/15	





# PATIENT PORTAL: MYCHILDRENSMERCY

It is important to keep all of your medical information together. One way to do this at Children's Mercy, and many other hospitals, is through something called a patient portal. The MyChildrensMercy Patient Portal is an online website where you can access your medical information. Learning to use this tool is great practice for adult care, as many adult hospitals will also have a patient portal for you to use.

Check out the website below for more information:  
[childrensmercy.org/MyChildrensMercy/](https://childrensmercy.org/MyChildrensMercy/)

## HOW DO I GET CONNECTED TO THE PATIENT PORTAL?

Once you are 13 or older, your parents or whoever has legal authority can give permission for you to use the patient portal. To get connected, that adult fills out a form using the web link above. You will need to include a copy of your signed form of identification (like a drivers' license or school ID) with the application.

You can do this while you are at the hospital, as well as by email, fax or mail. You will get an email invitation to connect to the patient portal. You must sign up within 90 days.

When you turn 18 you will need to re-register for the patient portal. At this time you will also decide if you would like your parents to have access to your portal account.

## WHAT CAN I DO ON THE PATIENT PORTAL?

You are able to see a list of your medications, see lab results, send a message to your health care team, see your medical information and list of medical problems, keep track of upcoming appointments, ask to reschedule an appointment, see your immunization history and more.

All information on the portal is put in by Children's Mercy staff; you are not able to change anything on your own.



## WHAT TO EXPECT: CHILDREN'S MERCY VS. ADULT HEALTH CARE

As you start talking about transitioning to adult care, it is important to talk about how an adult health care setting may be different than a pediatric setting like Children's Mercy. Not all experiences are the same, but the following are good things to think about and talk about with your health care providers.

AT CHILDREN'S MERCY	IN ADULT CARE
Focuses on the patient and family	Focuses more on the individual patient
Colorful and inviting environment	Might not feel as warm and welcoming
Parents/caregivers and health care providers help keep track of your medical care	Patients are responsible for their own care, with some support by health care providers and caregivers
Many support services offered (i.e., financial and emotional support)	Patients may need to ask for support services
Parents/caregivers are responsible for insurance and payment	Patient may be responsible for insurance and payment
Doctor will talk with patient and parents/caregivers about their care	Doctor will talk directly to patient about their care and expect the patient to make their own health care decisions
If a patient is under 18, parents/caregivers will need to be involved in care	If over the age of 18, patients must give permission for parents/caregivers to receive any medical information about the patient
Parents/caregivers request information about treatment and care options	Patient, maybe with support from the parent/caregiver, must ask about treatment and care options
Appointments are scheduled for the patient	Patients must schedule their own appointments

## FINDING A NEW DOCTOR

When working with your health care team to find an adult doctor, here is a list of things for you and your family to consider.

- Ask for a referral from your current doctor, plus recommendations from friends, neighbors and co-workers.
- Decide if you need a primary care doctor who can manage your overall health care and refer you to specialists, if needed. Or do you need a specialist in a particular area?
- Check to make sure your insurance plan will cover visits to the doctor you are considering.
- Think about where the doctor's office is located. Is it easy for you to get to, especially if you need to use public transportation?
- Schedule a first visit just to meet the doctor and talk. You may have to pay for the time, but it's worth it.
- Ask the doctor about his/her experience taking care of someone with your condition.
- What hospital does the doctor use and are you comfortable going there?
- Is routine lab work or X-rays done in the office, or do you have to go somewhere else?
- How long do you need to wait for a routine appointment?
- Can you get an appointment the same day if you are sick?
- Does the office charge a fee if you miss an appointment?
- Is the office staff friendly and efficient?
- Does the office have a system for reminding you of your appointment?
- Who covers for the doctor when he/she is away?
- If you call with a concern, who returns the call and how quickly?
- What technology is used? Is there a patient portal for lab results and questions – or is information relayed by phone or email?
- How compatible is the doctor's personality with yours?
- Take your treatment summary and list of medications to the first appointment. This will help you talk about your medical history and any current problems you have.

References: The Center for Children with Special Needs: Seattle Children's Hospital. Retrieved April 2016 from <http://www.cshcn.org>





[childrensmercy.org](https://childrensmercy.org)

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