



# Transition to Adulthood Education Resources

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# Transition Program

## 3 Sentence Summary:

Create to describe my medical problems to review with my providers.

### What is a 3-Sentence Summary?

The My Health 3-Sentence Summary provides some tips on how to describe your health and current needs in about 3 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:

1. Hi, my name is Sally Butamol. 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.

<b>Sentence 1:</b>	
<b>Sentence 2:</b>	
<b>Sentence 3:</b>	



# Transition Program

## Medical History and Condition:

Be able to describe my medical diagnosis and history.

As you get ready to switch to an adult doctor, it is very important to know your medical history and conditions. Be sure you know and tell your adult doctor.

Your medical condition(s): \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

List of your medication(s): \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Y/N** If you've ever spent the night at the hospital.

**Y/N** If you've had any surgeries, when they were: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

List of vaccinations you've received: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Any allergies you have: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

You can talk to your current doctor to get this information, or look at your medical history on the patient portal. Keep the information in a place that is easy for you to find.

**This is where I will keep my information:**



# Transition Program

## Medications:

Be able to name what medications I take. It is important to give a list to anyone involved in my health care.

Provide an updated list of your medicines to your new doctor(s), school nurse, and college campus health clinic. Make sure you know the following:

- The name of the medicine. (some are brand name, some are generic)
- The dose you take and when you take it.
  - » You can find this on the label of the medication.
  - » You can also ask your caregiver.
- How the medication affects you and your medical condition.
  - » A pharmacist or your doctor would be a good person to ask how your medication affects your body and medical condition.

## UNDERSTANDING YOUR MEDICATION BOTTLES

Pharmacy name and address

Number used by the pharmacy to identify this medication for your refills

Person who gets this medication

Instructions on how much and how often to take this medication

Name of medication and strength of medication

Number of refills before certain date

Doctor's name

Pharmacy phone number

Prescription fill date

Don't use this medication past this date





# Transition Program

## How to call the pharmacy:

Keep the pharmacy's number in your phone.

- **DO NOT WAIT** until you are out of medications to call in your refills!
- Find the phone number on the medication bottle:  
  
\*See bottle: \_\_\_\_\_
- You can speak to a pharmacist or you can use the automated system.
- Some pharmacies will send text reminders! See if your pharmacy has this program.

YOU

Hi, my name is (state your name) and i need to call in a refill.

PHARMACIST

Do you have a prescription number?

YOU

Yes, my prescription number is:  
\_\_\_\_\_  
\*See medication bottle example.  
When will my prescription be ready?

PHARMACIST

Would you like your prescription delivered or to be picked up?  
Would you like us to text you when your prescription is ready?



# Transition Program

## Alcohol, Drugs and Tobacco:

Explain how these could affect my medical problem.

### Using drugs, alcohol, or tobacco products can:

- Harm you.
- Make your medical problem worse.
- Change how you react or make decisions leading to car or other accidents.
- Having unsafe sex that can lead to an infection or unplanned pregnancy.
- Changes in your blood sugar (if you take diabetes medicines).
- Breathing problems and damage your lungs if you vape.
- Bad breath and problems with your teeth and mouth.

Talk with your provider about how drugs and alcohol can impact your medical conditions. Only take medications that are prescribed for you. Be sure your provider knows any over-the-counter medications you are taking. Even over the counter medications can cause problems.



# Transition Program

## Emergency Care and Asking for Help:

Ask my doctor and care givers to give me a list of signs that mean you need a doctor or nurse to check on you.

### In Case of Emergency:

- Ask your doctor and care givers to give you a list of signs that mean you need a doctor or nurse to check you. Also, ask what signs show you need emergency care.

Signs that I need to see a doctor:	Signs that I need to seek emergency care:
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>

- Who to call in an emergency:
  - » Make a list of people to call in an emergency and their phone numbers. This may include parent, guardian, sister, brother, doctor, and others:
    - **iPhone users:** Add these names and phone numbers to your Contact List. Then, click on "Add to Emergency Contacts"
    - **Android phone users:** Go to the app store and download Medical ID (Free) Contacts. Open the app and add these people.



- » Scan the QR code for more information on how to add emergency contacts.
- » Let each person know you list them as an emergency contact.

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- Know where there is an emergency room near you. One way is to type in "Emergency Rooms" to Maps or Google Maps. Be ready with this before an emergency starts.
- Practice explaining your health condition. This will help when you feel ill.

# Transition Program

## Contact Information and Insurance:

Keep a list of important contacts. Talk to my parent, guardian or social worker about what I need to do to be sure I have health insurance.

## Contacts & Phone Numbers:

- Keep a list of important contacts
  - » **Where?** Keep this in your wallet, phone, or another safe place
  - » **Who?** Doctors, nurses, school nurse, case managers and other important caregivers
- Other tips
  - » Add the phone numbers you need to set up a visit with your doctors.
  - » Remember: Make your doctors and other caregivers contacts in case of emergency.
  - » Put a link to your patient portal in the notes section of your doctor's contact.

## Insurance:

- It's important to have health insurance. Health care and medicines can cost a lot.
  - » Talk to your parent, guardian, or social worker about what you need to do to be sure you have health insurance.
- People have different ways of paying for their health care and medicine.
  - » Private insurance—such as Blue Cross, Aetna, or Cigna
  - » Public insurance—such as Medicare and Medicaid
- Most people need to change insurance at a certain age.
  - » Medicaid: It usually ends on the 19th birthday
  - » If you are on your parent's insurance: It usually ends on the 26th birthday
  - » Some young adults with special needs may be allowed to stay on their parent's private insurance.
  - » Ask a social worker or the parent's employer to learn more.
  - » Scan the QR code for additional resources to learn more about Medical Insurance Choices for Adults.





# Transition Program

## Contact Information and Insurance:

Keep a list of important contacts. Talk to my parent, guardian or social worker about what I need to do to be sure I have health insurance.

- **If you have insurance now:**

- » Keep your insurance card with you in a safe place (For example, in your wallet).
- » You will need it any time you see a doctor or get medications from the pharmacy.
- » **Find out:**
  - What your insurance pays for and what it does not pay for.
  - When the insurance ends.
  - What you will need to do to stay insured.

- **If you DO NOT have insurance now:**

- » Talk to your parent, guardian, or social worker about what you need to do to get insurance.
- » Find out what insurance plans your new doctors accept.
  - Visit [Healthcare.gov](https://www.healthcare.gov) or call 1-800-318-2596
  - To learn more about how insurance works, scan the QR codes to watch these videos
  - Health Insurance Coverage 101 - the Basics Explained in Two Minutes - YouTube
  - Understanding Your Health Insurance Costs | Consumer Reports - YouTube



# How to Read an Insurance Card

## + Provider

<b>1</b>	<b>Subscriber Name</b> JOHN DOE	<b>Group ID</b> 3095923	<b>4</b>
<b>2</b>	<b>Subscriber ID</b> MVP 402938716	<b>RxBIN</b> 005698	<b>5</b>
<b>3</b>	<b>Members</b> JANE LAUREN	<b>PCP/Specialist</b> Urgent Care Emergency Room Prescriptions	<b>6</b> <b>7</b>

**In / Out Of Network**  
0% / 20%  
50% / 75%  
70% / 85%  
\$5 / \$35 / \$70

**1** **Subscriber**  
The person who has the insurance policy.

**2** **Policy Number**  
The number for the policy. It is also called the Subscriber ID.

**3** **Members**  
All the people who are covered by this policy.

**4** **Group Number**  
The number that tells what employer or group you get the insurance from.

**5** **RxBIN Number**  
The number used to get prescription information to the right insurance.

**6** **Out-of-Pocket Costs**  
The amount you pay for health care services when you get care. This can be a total amount or a percentage (for example, you need to pay 10% of the bill).

**7** **Prescription Coverage**  
Tells what prescription medicines are covered. And what you pay by tier (often generic, brand name, and high cost).





# Transition Program

## My Health Passport:

Create and keep a copy in my wallet or copy it to my cell phone.

### What is a Health Passport?

- Personalized document where you can keep all your medical information.
- Useful for when you go to a new doctor, complete a health form, or visit an emergency room.

Transition Program


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**Health Passport**      Date: \_\_\_\_\_

(Enter Specialty Diagnosis)

**Name:** \_\_\_\_\_ **DOB:** \_\_\_\_\_

**Phone:** \_\_\_\_\_ **Email:** \_\_\_\_\_

**Insurance:** \_\_\_\_\_

\_\_\_\_\_ **Office Phone:** \_\_\_\_\_

(Enter Specialty)

**PCP:** \_\_\_\_\_ **Office Phone:** \_\_\_\_\_

**Pharmacy:** \_\_\_\_\_ **Office Phone:** \_\_\_\_\_

**Emergency Contact:** \_\_\_\_\_ **Contact Phone:** \_\_\_\_\_

**Guardian:** \_\_\_\_\_ **Contact Phone:** \_\_\_\_\_

Photo/Image of dx. example

Most prevalent test results related to dx.

(dx specific test results)      (dx specific test results)      (dx specific test results)

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**Allergies:** \_\_\_\_\_

**Medications:** \_\_\_\_\_

**Medical Devices:** \_\_\_\_\_

**Company:** \_\_\_\_\_

**DME Equipment:** \_\_\_\_\_

**Company:** \_\_\_\_\_

**Diagnosis-related Labs:** \_\_\_\_\_

**Oxygen:** Yes  No       **Baseline O2:** \_\_\_\_\_

**Activity Restrictions:** \_\_\_\_\_

**Pregnancy Considerations:** Yes  No       **Contraception:** \_\_\_\_\_

**Previous Tests/Procedures:** \_\_\_\_\_

**Follow-up Appointment Info:**

**\*\*Disclaimer:** This document is up to date as of \_\_\_\_\_ . Information is subject to change.

This is what the Health Passport looks like. Scan the QR below to download the file.





# Transition Program

## Patient Portal:

## Enroll and Explore.

The Children's Mercy Patient Portal is an online tool that gives you access to your health information 24 hours a day, 7 days a week. In the portal, you will be able to:

- Reschedule or cancel an appointment
- See your medication list
- View lab results
- Download visit summaries
- Send a message to your care providers
- See your immunization history

**You can access your patient portal on the Children's Mercy app or website. There are two ways to sign up for the Patient Portal:**

1. Stop at the clinic check-in desk. The Access Representative can help you sign up.
2. Start the enrollment process on [childrensmercy.org](https://www.childrensmercy.org) using this QR code.

For more information, call (816) 234-3455 or scan the QR code.



**If the young adult is not able to give consent, the legal guardian can register to access the patient portal. Once patients have turned 18 years old, they will need to grant parents/caregivers access to their patient portal. For more information on accessing accounts for patients over the age of 18, scan the QR code.**



# Transition Program

## Legal:

Be able to describe how my health care decisions will be made (Power of Attorney, Durable Power of Attorney, Supported Decision Making Agreement or Guardianship).

### Legal Issues:

- By law, people become adults at age 18.
- Some adults can make their own decisions, but others need help.
- A person they trust can be given the right to make decisions for them. This is called “guardianship.”
- If there is no legal plan in place, even the parent of an 18-year-old with special needs may not be allowed to see the health care records of their adult “child.”
- For more on this topic:
  - » Ask a social worker for help.
  - » Work with an agency or a lawyer that helps families make these legal plans.
  - » To see Children’s Mercy’s “Transition to Adulthood” webpage, scan the QR code.



### Key Legal Words to Ask About:

- Power of Attorney
- Durable Power of Attorney
- Supported Decision Making Agreement
- Full or Limited Guardianship

# Transition Program

## Adult Provider:

**Work with my team to find and contact a new adult provider.**

As you get older, you will need to transition from your pediatric doctors. You will need to find new doctors who care for adults. You will need a primary care doctor, specialty care doctors and mental health providers.

- Ask your pediatric doctors whom they suggest.
- You can also ask friends and family.
- You can search the Internet to find adult doctors.
- Children's Mercy also has a list of adult doctors on our website.
- Don't forget to check with your insurance to see if it will cover your new doctor.

Remember, you may need to visit more than one doctor before you find the best one for you. Scan the QR code for more information.



## Questions for a new adult medical provider:

1. Do you have experience with my medical condition?
2. Can I get an appointment quickly if I am sick?
3. How long does it take to get a routine appointment?
4. Is there a fee for a missed appointment?
5. Will you remind me of my appointment?
6. Who covers for the doctor when they are away?
7. How quickly will you return my call?
8. Do you have a patient portal?
9. Is clinic staff available after hours?

## Tips for preparing for the first medical appointment:

1. Write Down: questions you have for your new doctor
2. Keep: List of medications, take a picture of pill bottles on your phone
3. Enter your new doctor's contact information in your cell phone
4. Keep: a copy of your health insurance card and photo ID in your wallet
5. Keep: a copy of your medical summary from your pediatric provider
6. Find Out: where to go in case of an emergency
7. Sign Up: for new patient portal

# Transition Program

## Adult Provider (Medical Complexity):

Work with my team to find and contact a new adult provider.

As you get older, you will need to transition from your pediatric doctors. You will need to find new doctors who care for adults. You will need a primary care doctor, specialty care doctors and mental health providers.

- Ask your pediatric doctors whom they suggest.
- You can also ask friends and family.
- You can search the Internet to find adult doctors.
- Children's Mercy also has a list of adult doctors on our website.
- Don't forget to check with your insurance to see if it will cover your new doctor.

Remember, you may need to visit more than one doctor before you find the best one for you. Scan the QR code for more information.



## Questions for adult providers of young adults with medical complexity:

1. Do you have experience with my young adults medical dx or have a network of specialists you can refer to?
2. Do you have experience working with young adults with special health care needs and IDD?
3. Is your clinic set up to accommodate medical equipment?
4. Does your clinic have a wheelchair scale available?
5. Do you accept Medicaid? Do you accept my health insurance?
6. What hospital system do you refer to?
7. Can you refer to Care Coordination and/or Social Work for needed support?
8. Can I reach a provider after hours for a consultation in case of an emergency?
9. Can I call or email for non-emergent situations?
10. Are same-day appointments available if needed?
11. If you are unavailable, who should I expect to see instead?
12. Do you feel comfortable managing tube feedings?
13. Do you have access to a dietitian for consultation if needed?

# Transition Program

## Financial Planning:

Financial planning is important when your child has a disability or special health care needs. Caregivers want to make sure that their young adult has the highest quality of life. Keeping their benefits is essential. Special needs planning focuses on financial planning for the caregiver, the young adult, and when the caregiver can no longer provide on-going care.

### Resources to help start this process include:



**National Care Advisors**  
nationalcareadvisors.com



**Academy of Special Needs Planners**  
specialneedsanswers.com

Think about applying for an ABLE Account. An ABLE account is a savings account that allows someone with a disability to save money without effect on eligibility for certain government benefits.



**KS ABLE SAVINGS PLAN**  
savewithable.com/ks/home.html  
(888) 609-8919



**MO ABLE SAVING PLAN**  
moable.com  
(800) 439-1653





# Transition Program

## Accessible Transportation:

Accessible transportation is transportation for all. It can be by car, bus or sidewalk and can be used by everyone. People with disabilities may face transportation barriers. As some teens age it becomes harder for them to use a private vehicle. It can also be hard to transfer in and out of their wheelchair. Cars with accessibility features may help people with disabilities travel to work, school or their community on their own. It is important to make plans for accessible transportation as your young adult ages.



Talk to your Medicaid waiver support coordinator to see if there are funds available to modify their vehicle if funding is not available, or further help is needed. There are community resources to help, scan the QR code to learn more.



There are also accessible transportation options through the Kansas City Area Transportation Authority, scan the QR code to learn more

### Accessible transportation to medical visits is available through Medicaid. Before scheduling you will need this information:

1. Name of the and location of medical provider
2. Address
3. Phone Number

#### Who to call if you live in Kansas:

Aetna Better Health	1-866-252-5634
Sunflower	1-877-917-8162
United Health Care	1-877-796-5847

#### Who to call if you live in Missouri:

MO Health Net	1-866-269-5927
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# Transition Program

## Residential Planning:

Supporting your young adult as they age includes having a residential care plan for them as they get older. It is important for caregivers to remember that they know their situation better than anyone. There is no "Best" or "Right" answer.

### There are many possible living options. They can live:

- At home with modifications
- At home with In-home supports
- At home with Day programs or supported employment
- Independently with supports
- In residential care

### Include your care team and social supports in this decision. These people can include:

- You: \_\_\_\_\_
- Your young adult: \_\_\_\_\_
- Natural supports: \_\_\_\_\_  
\_\_\_\_\_
- Medical care team: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
- Waiver support coordinator: \_\_\_\_\_

Review this website for local vendors and grant opportunities if you do not have a waiver or funding source.



Community programs with Children's Mercy





# Transition Program

## Adult DME Providers:

As your young adult gets older, you will need to transition from your pediatric Durable Medical Equipment provider. You will need to find a new provider who provides equipment for adults.

- Ask your child's pediatric provider or clinical support specialist whom they suggest.
- Ask family and friends for any suggestions.
- Review your child's health insurance plan for in-network adult DME providers.
- Review Children's Mercy list of adult DME providers.

Remember, you may need to contact more than one provider before you find the best one for your young adult. Once you find an adult DME provider, tell your pediatric care team. They will make sure all needed orders are sent to the new provider.

Scan the QR code for tips on finding an adult-care provider.



# Transition Program

## Adult Pharmacy Providers:

As your young get older, you may need to transition from your pediatric pharmacy provider. Children's Mercy Outpatient Pharmacy does not fill prescriptions from providers outside of Children's Mercy. You will need to find a new pharmacy who provides services to adults.

- Ask your pediatric provider and pharmacist who they suggest. Talk with your current provider to see if you need to work with a compound pharmacy.
- Ask your family and friends for any suggestions.
- Review your health insurance plan for in-network adult pharmacy providers.
- Review Children's Mercy list of adult pharmacy providers.

Remember, you may need to contact more than one pharmacy before you find the best one for you. Once you find your new pharmacy, tell your current pharmacy provider. They will make sure all prescriptions are sent to the new provider.

Scan the QR code for tips on finding an adult-care provider.



# Transition Program

## Transition to Adulthood Roadmaps:

Roadmaps are made to help patients and families as a young adult moves into adulthood. Your medical team will help prepare young adults for the change from a pediatric model of care to an adult model of care.

A pediatric model of care is where parents or caregivers will make most choices.

An adult model of care is where the young adult will make their own choices.

### We have created 2 road maps:



**Transition to Adulthood Adolescent to Adult Road Map: Steps Along the Way for Teens Who Will Be Independent in Their Care**

**Age 15:** Introduce the program

**Age 15-17:** Know your conditions and medications, Meet close with your doctor, Know what to do in case of a medical emergency, Start participating in your medical care, Explain your medical condition to your care team, Understand test names and purposes, Continuing your medical team, Medication knowledge, Education and career planning, Self-advocacy, Health insurance, Basic needs and independence

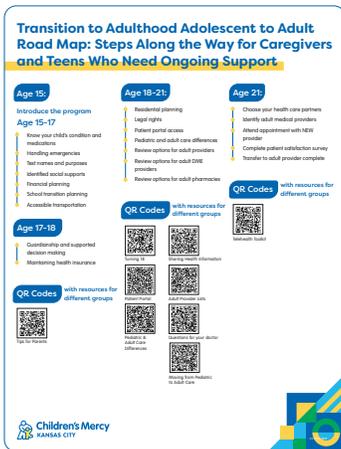
**Age 18-21:** Know legal rights, Consent to treatment, Update patient portal access, Review options for adult providers with your care team, Understand pediatric and adult care differences, Review questions to ask potential adult providers, Options for health insurance after age of 18, Be able to explain your medical history, Be able to explain how your medical condition affects your daily life, Be able to schedule medical appointments, Be able to fill medications at the pharmacy

**Age 21:** Choose your health care partners, Identify an adult medical provider, Test for successful first medical appointment, Attend appointment with NEW provider, Complete patient satisfaction survey, Transfer to adult provider complete

QR Codes with resources for different groups

Children's Mercy KANSAS CITY

**Transition to Adulthood Adolescent to Adult Road Map:**  
Steps Along the way for Teens who will be Independent in their care.

**Transition to Adulthood Adolescent to Adult Road Map: Steps Along the Way for Caregivers and Teens Who Need Ongoing Support**

**Age 15:** Introduce the program

**Age 15-17:** Know your child's condition and medications, Handling emergencies, Test names and purposes, Identify social supports, Financial planning, School transition planning, Accessible transportation

**Age 18-21:** Medication planning, Legal rights, Patient portal access, Pediatric and adult care differences, Review options for adult providers, Review options for adult DME providers, Review options for adult pharmacies

**Age 21:** Choose your health care partners, Identify adult medical providers, Attend appointment with adult provider, Complete patient satisfaction survey, Transfer to adult provider complete

**Age 17-18:** Questionnaire and supported decision making, Maintaining health insurance

QR Codes with resources for different groups

Children's Mercy KANSAS CITY

**Transition to Adulthood Adolescent to Adult Road Map:**  
Steps Along the Way for Caregivers and Teens need On-going Support.





# Transition Program

## Social Security Income:

Learn about Social Security Income and how to apply.

You may qualify for Supplemental Security Income (SSI). SSI is a needs-based disability program for adults and children. It provides monthly cash benefits. **The application needs to be completed around the time of the teens 18th birthday.**

To find more information:



Tips to prepare for SSI interview:





# Transition Program

## Medicaid Waivers:

Learn about Medicaid waiver programs for people with disabilities.

Waivers are Medicaid programs that help with care in a person's home or community.

They can provide more help with benefits that include:

- nursing and attendant care
- specialized medical supplies
- home modification

Missouri and Kansas both have waiver programs. Each state has a specific process for eligibility and to apply. The waiting list for Developmental Disabilities (DD) and Intellectual Disability (ID) waiver programs can be very long.

**If you want to apply, you should act early. People can be on one waiting list while receiving services from another program.**

### To find more information:



Missouri



Kansas

### For more questions please contact:



Missouri: Regional Office



Kansas: Community Developmental Disability Office