

# ARE YOU READY TO TAKE CHARGE OF YOUR HEALTH?

## 5 Steps to Prepare for Health Care Transition

At a time when there is a lot going on in the world and in health care, Got Transition is here to make one thing a little bit easier. Now may be a great time for young people to learn about their own health and plan for health care transition. This is the process of getting ready for health care as an adult.

This process involves gaining independent health care skills, preparing for an adult model of care, and eventually transferring to new providers. The steps and resources below can prepare youth, young adults, and families to make sure the transition to adult health care goes smoothly.

1



### ONLINE QUIZ

Are you ready to transition to adult care?  
Take our [\*online quiz\*](#) to find out now!

2



### TRANSITION TIMELINE

Know where you are before you can plan where you're going!  
Find out where you are in the transition to adult care by reviewing the [\*Transition Timeline\*](#) for age-specific milestones.

3



### READINESS ASSESSMENT

Find out what you already know about your health and health care by filling out our [\*Transition Readiness Assessment\*](#). Family members: fill out this [\*version for Parents/Caregivers\*](#) and compare your answers!

4



### GOAL SETTING

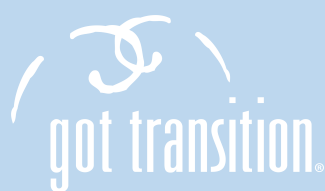
Setting goals is an important part of helping you reach independence in your medical care. Fill out this [\*helpful one-pager\*](#) from Children's Mercy Kansas City to set your health goals.

5



### TAKE YOUR HEALTH INFO WITH YOU

A smartphone is a great place to keep important health information. Fill out the [\*Medical ID\*](#) on your smartphone, which can be accessed by anyone in the case of an emergency.



For more information, visit [www.GotTransition.org](http://www.GotTransition.org)

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# MyHealth 3-Sentence SUMMARY



## What is a 3-Sentence Summary?

- ▶ An easy way to discuss important health information with your health-care team at each visit

**Good 2 Go**  
Transition Program



[www.sickkids.ca/good2go](http://www.sickkids.ca/good2go)

# SickKids®

## 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 this visit

## Example

***“Hi, my name is Sally Butamol.***

- 1) I am 16 and have asthma. I have been hospitalized twice, but not in the last 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



Completed by:

Date:

**Have ready:**

Calendar  
Your Insurance Card/Number  
Doctor's Name and Phone Number

**Call:**

Hello, my name is: *(your name)*

I would like to schedule an appointment with: *(doctor's name)*

Because: *(reason you want to see doctor. For example, check-up, headache)*

What times and dates are available?

*Check calendar: if not good say "Would you have another time available?"*

**Repeat back:**

My appointment is with:

Dr. *(name of doctor)*

on: *(date and time)*

*If you need accommodations (for example: lift, translator) tell secretary*

Thank you.

**Mark calendar:**

Name of Doctor:

Date and time:

**You May Be Asked:**

- To say your name again
- Your date of birth
- Last time you saw your doctor
- Your Insurance Number
- Your Phone Number

***After you hang up: make sure to schedule transportation!***



# Filling a Prescription

## *To Fill a Prescription (the medicine your doctor ordered)*

- ☐ Fill your prescription at the pharmacy or drugstore as soon as you can and start taking the medicine right away.
- ☐ Make sure the pharmacist knows all the medicines you take, including over-the-counter medicines like Tylenol or cold medicine.
- ☐ You may need to pay something (co-pay) to get your medicines.
- ☐ Ask questions to be sure you understand how to take your medicine and know what side effects to watch for. Don't sign for your medicine until you understand.
- ☐ If the pharmacy does not have the medicine your doctor has ordered or your insurance doesn't cover it, ask the pharmacy to call your doctor to discuss options.
- ☐ Make sure you are given the correct medicine.



## *Refilling a Prescription (getting more of the same medicine)*

- ☐ Know how you will order your refill:
  - **In person** - go to the pharmacy.
  - **By phone** - call the phone number on your medicine bottle to order a refill. You might get a recording that prompts you to press your prescription number and the time and date you will pick up your refill.
  - **By mail** - some insurance companies have mail-order choices that provide a three-month supply. If you want to use this option, you will need to ask your doctor to include a three-month supply on the prescription order. This may be cheaper.

## *When to Get Your Refill*

- ☐ **Keep track** (use a calendar, a pill sorter, or other reminder) of when you need to get refills to avoid running out and missing a dose of medicine. Missing doses can be bad for your health.
- ☐ **Check the label** on your medicine bottle to see how many refills you can get before your doctor will need to give you a new prescription.
- ☐ **Start your refill request about a week before running out of your medicine.** This routine will allow time to resolve any problems you may run into, such as insurance authorization, physician contact, or pharmacy supply.
- ☐ **Plan ahead: you may need your refill sooner than expected** (for example, if your dose changes or you need an extra supply to bring on vacation).

(Turn over for more tips and examples on filling a prescription)



## When Filling a Prescription

Pharmacy Name \_\_\_\_\_

Phone Number \_\_\_\_\_



Be ready to provide:

- ✓ Your name
- ✓ Name of medication
- ✓ Doctor's name
- ✓ Your insurance information
- ✓ Your prescription number (if refill)
- ✓ Date and time you will pick up your prescription

## Here is an Example Script for Getting a Prescription

**YOU:** "Hello, I need to fill this prescription." *(Give the prescription to the pharmacist)*

**Pharmacist:** "What is your name?"

**YOU:** "My name is \_\_\_\_\_." *(State your full name)*

**Pharmacist:** "What is your birthdate?"

**YOU:** "---- / ---- / ----." *(State month/day/year of your birthdate)*

**Pharmacist:** "What is your insurance information?"

**YOU:** \_\_\_\_\_. *(Give your information from your insurance card)*

**Pharmacist:** "The prescription will be ready in 15 minutes. When will you pick it up?"

**YOU:** "\_\_\_\_\_." *(State preferred pick up time)*

**Pharmacist:** "Do you have any questions?" (Examples: "Do I need to take this medicine with food? How long should I take this for? Are there side effects I should be aware of?" etc.)

**YOU:** "\_\_\_\_\_."

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# Health Care Transition Timeline

## for Parents/Caregivers

### Age 12-13

- Help your teen learn about their own health condition, medications, and allergies.
- Encourage your teen to ask their doctor questions about their own health.
- Ask your teen's doctor if and at what age they no longer care for young adults.

### Age 14-15

- Learn what your teen knows about their own health, health care, and family medical history. Both you and your teen can take Got Transition's Transition Readiness Assessments\* and discuss this together and with the doctor.
- Have your teen carry their own health insurance card.
- Help your teen learn more about their own health and what to do in case of an emergency.
- Help your teen practice making a doctor's appointment and ordering prescription refills (either by phone, online, or through an app).
- Encourage your teen to see the doctor alone for part of the doctor's visit to help gain independence in managing their own health and health care.

### Age 16-17

- Encourage your teen to make doctor's appointments, see the doctor alone, ask the doctor questions they may have, and refill medications.
- Ask the doctor to talk with your teen about their privacy rights when they turn 18.
- Work with your teen and the doctor to make and share a medical summary.
- Before your teen turns 18 and becomes a legal adult, figure out if they will need help making health care decisions. If so, ask your Family Voices chapter for local resources.
- Talk with your teen about the age they want to transfer to a new doctor for adult care.

### Age 18-21

- At age 18, your child is a legal adult and legally responsible for their care. You cannot access their medical information or be in the doctor's visit unless your young adult agrees or certain legal forms have been completed.
- If you need local resources on supported decision-making, ask your Family Voices chapter.
- Learn if there are additional changes at 18 that affect your young adult (e.g., health insurance, Social Security Income).
- Encourage your young adult to ask their current doctor to find a new adult doctor. Make sure that the new doctor accepts your young adult's health insurance, and help them learn if there are any charges at the visit.
- Encourage your young adult to keep a copy of their medical summary and always carry their health insurance information with them.

### Age 22-25

- Encourage your young adult to get care from their adult doctor, learn to manage their own health and health care, and update their medical summary.
- Encourage your young adult to stay insured. If they change health insurance, encourage them to make sure their doctor takes their insurance and learn if there are any charges at the visit.

\*For a Transition Readiness Assessment for youth, visit <https://gottransition.org/6ce/leaving-readiness-assessment-youth> and for a version for parents/caregivers, visit <https://gottransition.org/6ce/leaving-readiness-assessment-parent>.

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# What to Do In a Medical Emergency

## *Emergencies Can Happen at Any Time*

- **Plan Ahead** so if ever there is an emergency, you can **Act Fast** and **Stay Calm**.
- **Learn symptoms** that need **urgent medical** help, for example:
  - Sudden dizziness or fainting
  - Increased weakness
  - Change in level of awareness/alertness (hard to wake up)
  - Seizure
  - Hard time breathing
  - Feeling like you will hurt yourself
  - Severe allergic reaction
  - Sudden change in eyesight
  - High fever
  - Severe vomiting or diarrhea
  - Coughing up blood
  - Loss of consciousness
  - Severe burns



## *Always Be Prepared for an Emergency*

- Practice how you will tell others when you are having a medical emergency.
- Make sure you or somebody with you can explain ALL your health conditions and medicines.
- Be ready to **call 9-1-1** if you or someone else is badly hurt or in danger.
- Be sure to have an **In Case of Emergency (ICE)** name and number saved in your cell phone.
- Learn about symptoms that would need 9-1-1 and symptoms that could wait long enough to drive to the nearest emergency room.
- Talk with your doctor about wearing a medical alert bracelet if needed and ask your doctor or search the web to find a bracelet that fits your needs.
- Always carry identification, your insurance card, and your emergency care plan (if you have one).
- Know where the closest emergency room is to your home, job, and other places you spend time.

(Turn over for more practice tips and resources)



## Practice Giving the Information Needed When Calling 9-1-1

What is the emergency: \_\_\_\_\_

Your name: \_\_\_\_\_

Phone number: \_\_\_\_\_

Where you are: \_\_\_\_\_

Emergency contact and phone number: \_\_\_\_\_  
(parent, friend, roommate)

Who is with you: \_\_\_\_\_

Insurance information: \_\_\_\_\_

- When calling 9-1-1, stay on the phone until the operator says you can hang up.
- It might be helpful to write down your name, address, phone number, emergency contact phone number, and insurance information to keep near your home phone, in your wallet, or taped to your cell phone.



## Emergency Resources

The following resources might be helpful with planning for emergencies:

- Making a Family Emergency Plan: <http://www.ready.gov/america/makeaplan/index.html>
- Personal Preparedness Planning for People with Disabilities: [https://www.disability.gov/emergency\\_preparedness/personal\\_preparedness](https://www.disability.gov/emergency_preparedness/personal_preparedness)
- Making a First Aid Kit: <http://www.ready.gov/america/getakit/firstaidkit.html>
- The Emergency Preparedness for Children with Special Health Care Needs Form: <http://www.aap.org/advocacy/emergprep.htm>

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# My “Must Have” Papers

Community of Practice, Northeast Massachusetts 2011

*There are some papers that everybody must have. Here are some tips about keeping and protecting your important personal records and information.*

**Get a Binder or Folder to Keep Important Documents – an “accordion folder” works really well**

## What to Keep in Your Wallet or Purse

- ☐ State ID or Driver's License
- ☐ SNAP Card
- ☐ Health Insurance Card
- ☐ Important numbers
- ☐ Appointment Book / Calendar
- ☐ ATM Card (only if needed)
- ☐ Who to call in case of emergency
- ☐ List of medications & what doctor prescribes them.

## What to keep in your Binder

- ☐ Education documents
- ☐ Medical information
- ☐ Housing / Utilities information
- ☐ Work information
- ☐ Financial information
- ☐ Learn more about these on the other side of this paper



## Essential Documents to Have

These documents can help you get the other information you may need. You only need 2 of these to get a job and fill out the necessary paperwork.

- ☐ **Birth Certificate**
  - ☐ **Social Security Card**
  - ☐ **State ID or Drivers License**
- 
- ☐ **Passport:** This document can replace all of the essential documents listed above

**If you need to get your birth certificate:** Go to the Town Clerk or City Hall in the town/city you were born in and request it. If you were born further away you can contact the Town Clerk/City Hall (via internet or phone) and ask how to get it. Most often there is a fee (up to about \$25). You may also ask a DCF/DMH/DYS worker if they either have a copy or can assist you.

**If you need to get a License/ID/Permit:** Go to the Registry of Motor Vehicles (RMV). You will need the required ID. Sometimes if you don't have enough forms of ID (such as a birth certificate and social security card) a letter from DMH or DCF may be helpful explaining your situation. MASS.gov/RMV has more info about this.

**To get a social security card:** You, or your representative payee, will need to present your ID to the Social Security office and request a new card. (there is a limit to the number of cards you can request in your lifetime so it is important you keep it safe). Don't keep your social security card in your wallet unless you are using it that day to apply for a job- store it somewhere safe. Try to memorize the number.

**To get a passport:** Go to your local post office or check with your state's Passport Agency for details.

*If you keep information such as a social security number or bank information in your phone be sure to password protect it in case you get a new phone, or your phone is lost or stolen.*

# What to Keep in your Binder

## Education Documents (these are important for school, college, vocational programs, etc.)

- ☐ A copy of transcript from all schools attended or GED Certificate
- ☐ Most recent IEP or 504 Plan
- ☐ Any other certifications (CPR/First Aide), Vocational, CNA, Etc.
- ☐ College information: Financial aid information (including passwords), & transcript
- ☐ Print copies of any email confirmations you get & keep them too

## Medical Information

- ☐ Copy of most recent physical & immunizations (important for school & jobs)
- ☐ List of doctors names & numbers (keep a copy in your binder & your wallet)
- ☐ List of medications, times, dosages, & who prescribes them (keep a copy in your binder & your wallet)

## Work Information

- ☐ List of references – first & last names, their position, the company name, phone number, & dates worked
- ☐ Copy of letters of recommendations if you have them (don't give your last one away)
- ☐ Dates of places you have worked or volunteered & what your responsibilities were
- ☐ Work Permit – if you need it (you must get this through your school or city hall)

## Housing / Utilities Information

- ☐ Phone billing contracts & the most recent 2 bills
- ☐ Copy of your Lease
- ☐ Keep a list with your previous & current landlord's name, contact info, & the dates you lived there
- ☐ Most recent 2 gas, electric, cable bills & contracts
- ☐ Any housing list / subsidy information, copies of places you have applied
- ☐ Start & end dates to where you previously lived, the landlord name, phone number & a written reference is even better

## Financial Information

- ☐ A bank book or most recent statement
- ☐ Most recent Social Security award letter
- ☐ Keep all pay stubs
- ☐ Anything Social Security sends you
- ☐ All credit/debit card information
- ☐ Tax documents: Yearly W-2's, tax documents

**You can also make folder on your computer or email and keep a lot of this information there – like important emails or confirmations.**

## What information You Should NOT Give Out?

- Do not give out passwords (computer, PIN for Bank, Financial Aide, etc.)
- Keep passwords and logins in a safe place for your own personal use
- Social Security numbers (but sometimes it's OK, like on a job or housing application or for a bank application)
- Bank account information (unless for direct deposit of paychecks requested by employer)



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This publication can be made available in alternative formats upon request through [TransitionsRTC@umassmed.edu](mailto:TransitionsRTC@umassmed.edu)





## **FOR YOUTH AND YOUNG ADULTS: QUESTIONS TO ASK YOUR DOCTOR ABOUT TRANSITIONING TO ADULT HEALTH CARE\***

### **DURING YOUR ADOLESCENT YEARS:**

- ☐ When do I start to meet with you on my own for part of the visit to become more independent when it comes to my own health and health care?
- ☐ What do I need to learn to get ready for adult health care? Do you have a checklist of self-care skills that I need to learn?
- ☐ Can I work with you to prepare a medical summary for me and, if needed, a plan for what to do case of an emergency?
- ☐ When I turn 18, what information about privacy and consent do I need to know about? If I need help with making health decisions, where can I get information about this?
- ☐ At what age do I need to change to a new doctor for adult health care?
- ☐ Do you have any suggestions of adult doctors to transfer to?

### **BEFORE MAKING THE FIRST APPOINTMENT TO A NEW ADULT DOCTOR:**

- ☐ Do you take my health insurance? Do you require any payment at the time of the visit?
- ☐ Where is your office located? Is there parking or is it near a metro/bus stop?
- ☐ What are your office hours, and do you have walk-in times?
- ☐ What is your policy about making and cancelling appointments?
- ☐ How will I be able to communicate directly with the doctor after my visit or in the evenings?
- ☐ If needed, can the new adult doctor help me find adult specialty doctors?

### **BEFORE THE FIRST VISIT TO THE NEW ADULT DOCTOR:**

- ☐ Did you receive my medical summary from my pediatric doctor? (Call your pediatric doctor to remind them to send the medical summary before your first visit to the new adult doctor.)
- ☐ What should I bring to the first visit?
- ☐ Who can help me when you are not available?

**NOTES:** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

\*The American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians recommend that all youth and young adults work with their doctor or other health care provider to build independence and prepare for the transition to adult care. For more information about transition, please visit [gottransition.org/youth-and-young-adults](http://gottransition.org/youth-and-young-adults) and [gottransition.org/parents-caregivers](http://gottransition.org/parents-caregivers).



# Turning 18: What it Means for Your Health

Turning 18 may not make you feel any different, but legally, this means you are an adult.

## What does this mean?

- After you turn 18, your doctor talks to **you**, not your parents, about your health.
- Your health information and medical records are private (or confidential) and can't be shared unless you give the OK.
- It is up to you to make decisions for your own health care, although you can always ask others for help.

## Things to know

- The confidentiality between you and your doctor is legally known as the Health Insurance Portability and Accessibility Act, or HIPAA.
- This law gives privacy rights to minors (people who are under age 18) for reproductive and sexual health, mental health, and substance abuse services. Check your state's minor consent laws for more information.

## What needs to be done?

- If you want to share medical information with others, your doctor will ask you to fill out a form that allows them to see your medical record and be with you during your visit.
- If you need help making decisions, talk to your family, your support team, and your doctor about who needs to be involved and what you need to do to make sure they can be a part of the conversations.

## Additional resources

- If you want extra support managing your health or making decisions, the [National Resource Center for Supported Decision-Making](https://www.gottransition.org/) has information to connect you with resources in your state.

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## Intellectual Disabilities/Developmental Disabilities (ID/DD)

### Developed by:

American Academy of Family Physicians  
American Academy of Pediatrics  
American College of Physicians  
American Osteopathic Association  
Got Transition/Center for Health Care Transition  
Health Care Transitions Research Network  
Medicine-Pediatrics Program Directors Association  
Society for Adolescent Health and Medicine  
Society of General Internal Medicine

**How Developed:** Young Adults with intellectual disabilities or other developmental disabilities face many challenges as they strive to transition from childhood to adulthood. Along with striving for greater independence and to participate in the educational, vocational, and social activities typical for their age, they also have to move from the pediatric providers that have cared for them to new adult providers. This transition can be difficult for all involved due to some of the unique needs of these young adults. In order to help facilitate this transition and ensure good communication and care coordination, the primary care work group developed tools specific to the needs of young adults with intellectual disabilities or other developmental disabilities. The work group included input from primary care providers and young adults as well.

Tool Name	Description of Tool	How to Use Tool
<a href="#"><u>Transition Readiness Assessment for Youth with Intellectual Disabilities or Developmental Disabilities (Pediatric)</u></a>	<p>*Modified to a 4<sup>th</sup>-grade literacy level</p> <p>An assessment tool intended to be filled out by the intellectually disabled youth and utilized by the pediatric care team or other clinicians caring for youth to begin the conversation about the youth's needed skills to manage his/her health and health care. This tool indicates the elements specifically related to the clinical condition that should be assessed and documented by the transferring pediatric practice.</p>	<p>This <a href="#"><u>form</u></a> is suggested to help assess the <u>teen/emerging young adult's</u> knowledge of their health care needs and their skills in managing them. It is intended to be given to the adolescent patient as early as age 14 and intermittently thereafter up until the time the patient transfers to an adult provider. Useful as a guide for the provider, patient, and their family's efforts to help the teen develop skills identified as areas of concern. A final assessment prior to transfer will provide important information for the pediatric team to convey to their adult counterparts.</p>





<p><u><a href="#">Transition Readiness Assessment for Parents and Caregivers of Youth with Intellectual Disabilities or Developmental Disabilities (Pediatric)</a></u></p>	<p>An assessment tool intended to be filled out by parents and/or caregivers and utilized by the pediatric care team or other clinicians caring for youth to begin the conversation about the youth's needed skills to manage his/her health and health care. This tool indicates the elements specifically related to the clinical condition that should be assessed and documented by the transferring pediatric practice.</p>	<p>This <a href="#">form</a> is suggested to help assess the <u>parent/caregiver's</u> opinion of the teen/emerging young adult's knowledge of their health care needs and their skills in managing them. The tool is intended to be given to the parent/caregiver starting when the patient is age 14 and intermittently thereafter up until the time the patient transfers to an adult provider. It can be used to guide the provider, patient, and their family's efforts to help the teen develop skills identified as areas of concern. A final assessment prior to transfer will provide important information for the pediatric team to convey to their adult counterparts.</p>
<p><u><a href="#">Medical Summary for Young Adults with Intellectual Disabilities or Developmental Disabilities (Essential Clinical Information)</a></u></p>	<p>A medical record summary that indicates essential clinical information specifically related to the clinical condition that is to be included in the patient's medical record upon transfer to the adult practice.</p>	<p>The clinical summary/transfer record <a href="#">form</a> should be completed, signed, and dated on last page by the referring provider and patient at the time of transfer. At this time the form should be given to the new adult providers prior to the first visit. The form can be completed before the time of transition and used as a tool to help the young adult to become familiar with their health care plan and needs as part of the process of developing the knowledge and skills they will need to assume responsibility for their own health.</p>



<p><u><a href="#">Self-Care Assessment for Young Adults with Intellectual Disabilities or Developmental Disabilities</a></u></p>	<p>*Modified to a 4<sup>th</sup>-grade literacy level</p> <p>An assessment tool to be filled out by the intellectually disabled youth and utilized by the adult care team to assess any remaining gaps in self-care knowledge and skills or additional issues that need to be addressed to ensure optimal management of the medical condition(s).</p>	<p>This <u><a href="#">tool</a></u> should be given by the adult health care team to the young adult once they establish care. Its purpose is to help the adult provider and their practice and the young adults to better understand what areas the young adult will need assistance and support with to ensure that their care quality remains high and to help determine areas for continued education and skill development.</p>
<p><u><a href="#">Self-Care Assessment for Parents or Caregivers of Young Adults with Intellectual Disabilities or Developmental Disabilities</a></u></p>	<p>An assessment tool to be filled out by a parent and/or caregiver of an intellectually disabled youth and utilized by the adult care team to assess any remaining gaps in self-care knowledge and skills or additional issues that need to be addressed to ensure optimal management of the medical condition(s).</p>	<p>This <u><a href="#">tool</a></u> should be given by the adult health care team to the young adult once they establish care. Its purpose is to help the adult clinician and their practice and the young adults to better understand what areas the young adult will need assistance and support with to ensure that their care quality remains high and to help determine areas for continued education and skill development.</p>