



Transitioning to Adult Care: Managing Your Health Condition Independently

Dear Patient and Family,

Learning how to manage your health and wellness is key to transitioning to adult care (or healthcare transition). As you get closer to becoming a young adult, you will begin to be more involved in managing your health and making medical decisions. This guide includes tools to help you and family learn about talking with your health care team, what to expect when you move to adult care, and building skills to manage your health.

Your Children's Health Care Team wants to help you be ready and are here to help you make the transition to adult care. Talk with us if you have any questions.

Sincerely,

Children's Health

Skills for Managing Your Health Condition Independently

As you get closer to becoming a young adult, you will begin to be more involved in managing your health and making medical choices. Below are skills and tips to help you start managing your health.

Skills to Practice

- **Talk to your health care team.**
 - On your visits, begin to answer questions from your health care team about your health, medical history, and medicines.
 - Also ask your health care team any questions you have about your health.
 - Practice checking into your next visits on your own.
- **Understand your health care rights.**
 - When you turn 18 years old, you will be an adult and will be responsible for making medical decisions about your own health.
 - You will sign consents for treatment and decide who you want to share your medical information with and how it can be shared.
 - Talk with your health care team and parents and caregivers about your health care rights and making medical decisions in the future.
- **Learn the differences between pediatric and adult care.**
 - Talk with your health care team, parents and caregivers about what to expect when you move from your pediatric doctor to an adult doctor.
- **Learn how to refill your medicine.**
 - Watch and listen as your parents and caregivers refill your medicine.
 - Practice calling the pharmacy with your parents and caregivers the next time you need a refill.
- **Know your health care team and their role in caring for your medical condition.**
 - Learn the names of your health care team and how they help you.
 - Your health care team could include your primary care doctor, specialists, nurses, social workers, child life specialists, psychologists, care coordinators, or dieticians.

Skills for Managing Your Health Condition Independently (continued)

- **Learn when and how to contact your health care team.**
 - Talk to your health care team about when you should contact them with your questions or concerns.
 - Ask for their contact information so that you can reach out to them if you need their help managing your health.
 - Have your health care team phone number in your wallet or on your phone.
- **Learn how to schedule a visit.**
 - Watch and listen as your parents or caregivers schedule a visit with your doctor.
 - Practice calling the clinic or logging on to your patient portal with your parents and caregivers the next time you need a visit.
 - Next time, try to schedule your visit with the support of your parents and caregivers.
- **Know when you need to go to the Emergency Room.**
 - Talk with your health care team, parents and caregivers about what to do if you need emergency care.
 - Learn where the nearest emergency room is located.
 - Identify someone to call and inform of your emergency.
- **Start planning how to get to and from your doctor's visit.**
 - Talk with your health care team, and parents and caregivers about your transportation options for visits.
 - Practice setting up transportation with your parents and caregivers the next time you need to get to a visit.

Talking to My Health Care Team

As you begin to take charge of your health, it is important to talk with your doctors and health care teams during clinic visits. In the past your parents or caregivers have talked directly with your health care teams. In adult care you will be the main “go-to” person your health care team will talk to about your health.

Before your visit:

- Think about questions your health care team may ask you and how you would answer them. This can include:
 - What is your health condition?
 - What are past surgeries and procedures you have had?
 - What are the medicines you are taking, including the names, amount, and reason you are taking them?
 - Has anything changed since your last visit?
- Think about questions you have for your health care team. This can include:
 - What is my main problem?
 - What do I need to do?
 - Why is it important for me to do this?
 - What should I do if I have a new concern or problem?
 - How often do they want to see me?
 - When and who to call to get medicine refills?
 - What to do in an emergency?
- Think about the things that you don’t understand about your health condition.
 - Changes in your care.
 - Ask for more Information or education.
- Write down at least three questions to ask your health care team during your visit and take them with you. You can use the questions above if you need help.

During your visit:

- Answer questions from your health care team about your health, medical history, and medicines.
- Ask your health care team any questions you have about your health.
- Don’t feel rushed, nervous, or embarrassed to ask questions. Your health care team wants to help you.

After your visit:

- Contact your healthcare team with any follow up or new questions.

One on One Time with Your Health Care Team

See if your clinic will allow you to have one-on-one time with the doctor?

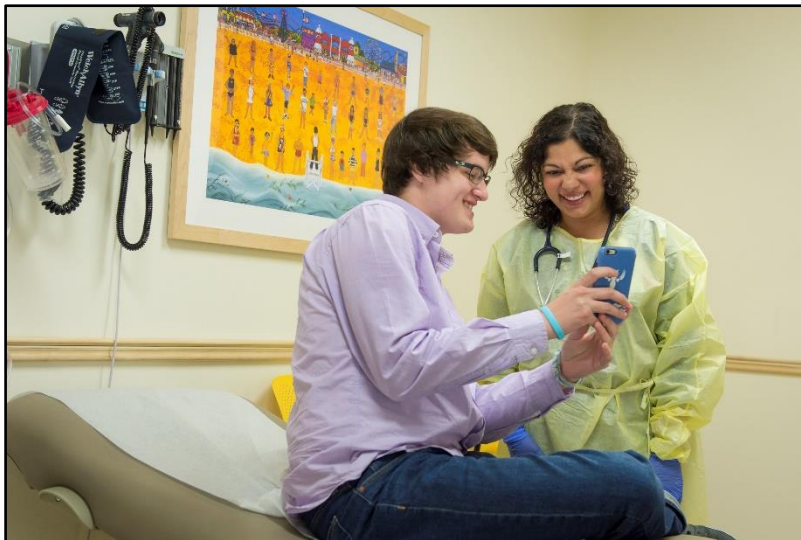
- As you get older and take charge of your health, it will be important to talk with your doctors and health care teams during clinic visits.
- One-on-one time with your doctors and care teams gives you the chance to learn more and talk privately about your health and medical needs.

What should I expect during one-on-one time?

- You will be the main person to about your health.
- You have a say in making decisions about your health.
- Your parents/caregivers will be there for support.

How to get ready for your visit

- Before your visit ask your parents/caregivers about your:
 - Medical History
 - Medicines
 - Name of medicine
 - Strength (mg)
 - When you take them
 - Why you take them
- **Think about questions you want to ask:**
 - When and who to call to get your medicine refills?
 - What to do if you have a new concern or problem?
 - How often they want to see you?
 - What to do in an emergency?



My Health Care Related Rights

At the age of 18, you become a legal adult. As an adult, you will be in charge of making decisions about your health care. Making decisions for yourself about your health care is a health care right. Another health care right you have is deciding who you want to share your health information with.

Your health information is private (or confidential) and cannot be shared with others unless you tell your doctor to share it. It is protected by law and the confidentiality between you and your doctor is legally known as the Health Insurance Portability and Accessibility Act, or HIPAA.

- At your visits, you will be making medical decisions but can always ask others for help. You will also choose who you want to be involved in your care.
- You will sign a consent for treatment. When you sign a consent for treatment, you:
 - Give your health care team permission to treat you.
 - Give your health care team permission to share your protected health information (PHI) as needed for treatment purposes.
 - Give your health care team permission to share your health information with others.
 - Accept that you will be in charge of the payment of the treatment provided.
- You will decide who has access to your health information including your patient portal (MyChart).
- You will need to give permission to your health care team to share your health information with your parents or caregivers, family, or friends. Since your health information is private, you will have to sign releases of information or permission forms to allow the health care team to speak to others about your health care.

Filling and Refilling My Medicine (Prescription)

Part of managing your health condition is making sure you have the medicine you need and knowing how to get more. Medicine ordered by your doctor and given to you by a pharmacy is called a prescription. Ordering a new medicine or asking for more medicine is called filling or refilling your prescription. As you begin to take charge of your health, it is important to learn how to fill and refill a prescription. Below are steps to help fill and refill a prescription.

Filling a new prescription

- Your doctor will order a new prescription by:
 - calling your pharmacy,
 - sending an order through the electronic medical record (EMR), or
 - giving you an order to take to the pharmacy.
- You will need to give the doctor the name and address of your pharmacy.
- The pharmacy will call, text, or send a message that your prescription is ready.
- You will pick up the prescription from the pharmacy.

Refilling a prescription

- Have the following information ready before you call your pharmacy:
 - Pharmacy name and phone number
 - Your full name and date of birth
 - Name of medicine
 - Doctor's name
 - Your prescription insurance information
 - Prescription (Rx) number (can be found on medicine bottle)
 - Date and time you will pick up the prescription
- The pharmacy will call, text, or send a message that your prescription is ready.
- You will pick up the prescription from the pharmacy.

Picking up prescription

- Have a way to pay for your prescription. (Credit card, debit card, or cash)
- Pick up your prescription by the date you need it or when the pharmacy says it will be ready.
- Information the pharmacy may ask you can include:
 - Your full name and date of birth
 - Your prescription insurance information
 - Name of the medicine or prescription (Rx) number (can be found on medicine bottle).
- You will meet with a pharmacist who can tell you about your prescription and help answer any questions. This can include:
 - Do I need to take medicine with food?
 - How often will I take the medicine?
 - Are there side-effects to taking this medicine?

Filling and Refilling My Medicine (Prescription) (continued)

Tips for filling or refilling a prescription

- Watch a parent or caregiver call to get a prescription refilled.
- Watch a parent or caregiver pick up a prescription.
- Have your parent or caregiver help you fill or refill a prescription, with you taking the lead.
- Know what your medicine looks like, so you know if the pharmacy gives you something different.
- See if a prescription can be mailed to you.
- Ask your pharmacy if your prescription can be automatically refilled.

Knowing My Health Care Team

Your health care team includes all the people at the hospital and clinics that work together to help care for you. Each person in your health care has special training. It's important to learn who is in your health care team, how they help you, and how to contact them if you need them.

Primary Care Provider (PCP): The primary or main doctor that cares for you when you are both sick and well. A PCP will see you for checkups and sick visits and helps coordinate your health care.

Specialist: A doctor that cares for your medical needs related to your specific health condition. Specialists can include Neurology, Pulmonary, Endocrinology, Gastroenterology, Cardiology, Nephrology, and Rheumatology.

Surgeon: A doctor that specializes in performing surgeries.

Dentist: A doctor that takes care of your teeth and gums.

Advanced Practice Provider: Examples include: Physician Assistant (PA), Nurse Practitioner (NP), and Certified Nurse Specialist (CNS). These are licensed health care providers who have specialized training who can help you manage your medical condition and medicines.

Nurse: A licensed professional who cares for you when you are not feeling well, helps you manage your health condition, and provides education.

Care Coordinator: A licensed nurse who organizes your care with doctors and arranges your other needs such as medical equipment.

Chaplin: A trained professional who provides religious, spiritual, and emotional support.

Child Life Specialist: Members of the health care team trained in child development and growth who provide education, coping skills, and support.

Dietitian: Experts on food and nutrition who help you learn about your nutritional needs and eating healthy.

Medical Assistant: Works alongside doctors and nurses in clinics. They may take your vitals and prepare you for your visit.

Pharmacist: Prepares your medicine when ordered by your doctor and provides education about your medicine.

Social Work: Members of the health care team who provide services and supports such as, counseling, support groups, discharge and home healthcare planning, financial assistance, lodging assistance and referral to appropriate community resources and programs.

Knowing My Health Care Team (continued)

Therapist: Examples include Occupational Therapist (OT), Physical Therapist (PT), and Speech Language Pathologist (SLP). These are licensed health care providers who specialize in assessing and providing treatment, rehabilitation, or therapy.

Mental Health Professionals: Can help you set goals, understand your own concerns, and learn new coping skills. These providers can include:

- **Licensed Clinical Social Worker (LCSW):** A counselor with a master's degree in social work. Trained to make diagnoses, provide individual and group counseling, and provide case management and advocacy, they are usually found in the hospital setting.
- **Licensed Professional Counselor (LPC):** A counselor with a master's degree in psychology, counseling or a related field who is trained to diagnose and provide individual and group counseling.
- **Psychiatrist:** A medical doctor with special training in the diagnosis and treatment of mental and emotional illnesses. A psychiatrist can evaluate and diagnose patients, prescribe medication and sometimes provide therapy service.
- **Psychologist:** A professional with a doctoral degree in psychology, psychologists specialize in the study of behaviors and mental processes. Psychologists help people learn to understand and handle different life problems and mental health issues. They also provide psychological assessments to assess cognitive and emotional functioning.

Remember to:

- Keep the names and phone numbers of your health care team with you at all times. You can add these into your phone, smart device, or carry a written list in your wallet.
- Add the names and phone numbers of your health care team to your medical summary.
- Ask your health care team when you should reach out for their help.
- Your health care team can also include care coordinators from your health insurance who can help manage your care and answer questions about your health insurance.

Scheduling My Own Visits

As you begin to manage your health, it is important to learn how to schedule your own visits. In the past your parents or caregivers have scheduled visits for you. When you move to adult care, your health care team will want you to contact them and be able to schedule visits on your own.

Below is the information you may need to give the clinic when you call to schedule a visit:

- Your full, legal name.
- Your date of birth or medical record number (MRN).
- Your doctor's name.
- Reason for visit. (Examples can include annual checkup or sick visit).
- Dates and times when you are available for your visit. (Depending on the reason for visit this may include as soon as possible).
- Extra help or equipment needed on the visit.
- Name of health insurance and member ID number. (Have health insurance card with you when scheduling visit).

Before you end the phone call:

- Ask if you need to bring anything for the visit or if there are any special instructions.
- Write down the date and time of the visit.
- Write down any other important details about your visit.
- Repeat the information back to the clinic staff.
- Put the visit date and time on your calendar or in your phone.
- Set a reminder on your phone or smart device.

Remember to:

- Add the phone numbers of the clinic to your phone.
- Ask your care team about scheduling visits online or through patient portal (MyChart).
- Confirm your scheduled visit through phone call, text, or patient portal.
- Call the clinic immediately if you need to cancel or reschedule visit.
- Watch a parent or caregiver call to schedule a visit.
- Have your parents or caregivers help you schedule a visit, with you taking the lead.

What to Expect When You Move to Adult Health Care

There are differences between pediatric to adult care. Below are some of the biggest changes that will happen when you move to adult care. Talk to your pediatric health care team if you have questions about what to expect when you move to adult care.

- **Talking with your health care team**
 - Your health care team will want to hear directly from you. This includes talking directly with you during visits, scheduling your own visits, and sending messages through the patient portal (My Chart). You will be the go-to person driving your care.
 - Your health care team will want you to answer questions about your health condition, medical history, and medicines.
 - Your health care team will want you to ask them questions about your health.
 - Parents or caregivers can be included in your visit for support if you give permission.
- **Medical decision making**
 - At your visits, you will be making medical decisions and signing consents for treatment.
 - You will decide who has access to your health information including your patient portal (MyChart).
 - You will need to give permission to your health care team to share your health information with your parents or caregivers, family, or friends.
- **Health insurance**
 - Know your health insurance and bring your health insurance card with you.
 - Understand your health insurance and what it pays for.
 - Know if payment is required and how you will pay for it at the time of your visit. This payment could be a co-pay, coinsurance, or deductible.
 - Identify when your current health insurance will end and how to access new health insurance, if needed.
- **Care provided by PCP and specialists**
 - Your PCP can care for many of your health care needs and a fewer number of specialists may be needed.
 - You may have face-to-face and virtual visits. Some of your visits may be shorter in length.
 - Advocate for yourself by letting your health care team know if you need additional resources, services, or supports.

When and How to Access Emergency Care

Sometimes your health condition can change, and you may need to seek care outside of regular medical visits with PCP or Specialist. Talk to your health care team about creating a plan that includes when, where, and how to get to care when you need it. Below are questions to ask your health care team and parents or caregivers.

- When should I seek care?
- Should I go to an emergency room (ER) or urgent care?
- Where will I go?
- Which one is closest to me?
- Who will I call? Should I call my parents or caregivers, health care team, or 911?
- How will I get there?
- What are the important things I need to tell the doctors and staff when I arrive? Examples can include diagnosis or health condition, special medical equipment, and medicines I am taking.
- Do I need to contact my health care team after I have arrived at ER or urgent care? If yes, when and how should I contact them.

Setting Up Transportation

Part of managing your health condition is attending your scheduled visits and knowing how you will get to and from your visits. In the past, your parents or caregivers have planned how you get to your scheduled visits. Talk to your health care team, parents or caregivers about creating a plan for how to get to your scheduled visits when you move to adult care. Below are questions to think about as you create a plan.

- How do I get to my visits now?
- Will how I get to my visits change when I move to adult care?
- If yes, how will I get to my visits when I move to adult care?
- Do I need help to get to my visits?
- If so, who can help me?
- What is my backup plan for getting to and from visits?

Medicaid Patients Only:

If you have Medicaid and need transportation, call:
1-877-633-8747 or (1-877-MED-TRIP)

Call the Medicaid number 1 week before your medical appointment to set it up. Have the following information ready when you call:

- Medicaid ID or CSHCN program number.
- The address where you will be picked up.
- The name, address, and phone number where you need to go.
- Date and time you need to get to your appointment. Plan to get there 30 minutes before your appointment.
- Tell them about any special needs you have. (Example: Wheelchair)

If you use Medicaid transportation, ask your parents or caregivers to show you how they set up your transportation. Then practice as they watch.

Transition Tips for Parents and Caregivers Managing Health Conditions Independently

As your teen begins to learn about their health condition and medicines, it is also important that they begin to learn how to manage their health as independently as possible. Below are skills and tips to support your teen.

- **Talking to their health care team.**
 - Help your teen talk directly to their health care team and let them answer any questions the health care team has about their health.
 - Have your teen write down questions to ask their doctor or health care team at their next appointment.
- **Understanding their health-related rights.**
 - When your teen turns 18 years old, they will be an adult and will be responsible for making medical decision on their own.
 - They will also begin to sign their own consents for treatment and decide who they want to share their medical information with and how it can be shared.
 - If your teen is unable to make medical decision for themselves, legal tools for medical decision-making must be in place, if needed.
- **Learning the differences between pediatric and adult health care.**
 - Talk about what to expect when they transfer from a pediatric doctor to an adult doctor.
- **Learning how to refill their medicines.**
 - Let them watch and listen as you refill medicines.
 - Let them practice calling the pharmacy with you, as they are able, the next time a refill is needed.
- **Knowing their health care team and their role in caring for your teen's health condition.**
 - Help your teen learn the names of their health care team and how they help care for them.
 - This team could include a primary care doctor, specialists, nurses, social workers, child life specialists, psychologists, care coordinators, or dietitians.
- **Learning when and how to contact their health care team.**
 - Talk with your teen about when they should contact their health care team.
 - Help them gather their contact information so that they can reach out if help managing their health is needed.

Transition Tips for Parents and Caregivers Managing Health Conditions Independently

- **Learning how to schedule their visit.**
 - Talk to your teen about making a visit with their doctor office.
 - Have your teen practice calling the clinic or logging on to their patient portal the next time they are needing a visit.
- **Knowing when they need to go to an emergency room.**
 - Talk with your teen about what to do if they need emergency care.
 - Help them locate the nearest emergency room.
 - Talk about who to call if they have an emergency.
- **Knowing how they will be getting to and from doctor's visits.**
 - Talk with your teen about transportation to and from doctor's visits.
 - If you set up transportation, let your teen watch and listen to how you set up transportation.
 - Let them practice setting up transportation with your support the next time transportation needs to be scheduled.



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