



Boston Children's Hospital
Social Work Transition Committee



Transfer of Care to Adult Providers

A Guide for Young Adults



Growing up and moving *on*...



Becoming an adult can be an exciting time but also stressful as you make more decisions for yourself. For teens and young adults with special health care needs, this can be an even more stressful time, because you are leaving a team of care providers who you know well, and who have helped you stay healthy.

We acknowledge how important and meaningful this relationship is for you and your family. It is often just as difficult for us as providers when patients move on to adult medical care. The best "graduation" gift we can give you is the chance to make a smooth transfer of care by giving you the tools to make a successful transition. Please ask your care team questions and share your concerns.

We hope you find this guide useful. We are honored to go alongside you as you prepare to travel your own path into the adult world.

Introduction

What is transfer of care?

Transfer of care is a change from a pediatric doctor to an adult doctor. The transfer to a new provider comes toward the end of a process of transition, where you take ownership of your health over time as you prepare for adult life.

Why do I need to transfer my care?

The goal is for you to always be seen by the doctors that can best help you at your current developmental stage. Many primary care and specialty doctors who see children (pediatricians) are not trained to care for adults. When you reach adulthood, it may be best that you are seen by doctors who are experts in providing care to adults.

It is important to have a provider who can help you manage medical concerns, who also addresses topics including sexuality, substance use, relationships, employment, family planning and long- term management of health issues that affect an adult body.

What does the transition include?

The transition and transfer of care is slow and won't happen overnight. The process is different for everybody. If you are your own guardian, there will be a transfer of responsibilities from your parent(s) to you. These include consenting (agreeing) for care. Some tasks that become your responsibility are scheduling appointments, communicating with providers and getting medications refilled.

How should transferring care begin?

During the transition process, it is best to take small steps to slowly start managing your own health needs. Taking on too much too fast can be overwhelming. The best way to have a smooth transfer of care is to do it **slowly** and **with planning** so that your care is not disrupted.

What's the difference?

Specialists

In **pediatric hospitals**, there are many multi-disciplinary clinics. A single appointment might include visits with several specialists. In **adult hospitals**, it is much more common for each specialist to work individually.

Role of PCP

Pediatric specialists may provide care coordination without needing to involve the pediatrician. **Adult specialists** typically make recommendations, but much of the care coordination is done by the primary care provider (PCP).

Care Model

Pediatric care uses a family-centered model. **Adult care** follows more of a problem-focused model.

Appointment Time

Typical appointments with **pediatricians** are 15-45 minutes. Typical appointment lengths with pediatric specialists are 45-60 minutes. Typical appointment lengths with **primary care providers** are 15-20 minutes. Typical appointment lengths with adult specialists are 30-45 minutes.

Resources

In **pediatric care**, there are typically more supports, such as social workers and resources specialists, to help families between appointments. The supports available in **adult primary care** vary. Practices designated as Patient-Centered Medical Homes offer the most support. Adult specialists are less likely to have access to social workers and other psychosocial supports.

What does all this mean?



When transferring to adult care, you may see fewer specialty physicians because your primary care physician may manage many chronic health conditions. This also means that the role of your primary care physician is even more important. You can (and should!) speak up as you work with your new primary care physician to coordinate your health care needs. **Did you know?** Your health information or encounters may still be shared with the insurance policy holder (this could be your parents) for payment reasons.

Adult Primary Care Physicians

Who finds my new PCP and specialists?

As your own legal guardian, you will ultimately be responsible for finding a primary care physician and adult specialists with whom you feel comfortable and for taking care of the details, like making sure they accept your insurance. You should work with your parents, other support people and your current providers to get ideas. Start the conversation early so you can work together and prepare in advance.

How to find a primary care physician

- **Ask your pediatrician** for recommendations for adult primary care providers.
- **Ask your insurance company** for recommendations of practices accepting new patients.
- **Ask relatives and friends** if they recommend their own doctors.

How to find an adult specialist

- **Ask your pediatric specialist** for recommendations for adult specialists.
- **Ask your insurance company** for recommendations of adult specialists accepting new patients.
- **If there is a national organization** for your medical condition (such as the Spina Bifida Association or United Cerebral Palsy), contact them for recommendations.

Rare conditions

It can be hard to find adult specialists for certain kinds of rare medical conditions. It is important to start talking with your pediatric specialists early as you start to look for adult specialists. There may be a period of time when you see both pediatric and adult specialists as part of a slow transfer process.

& Specialists

Different types of primary care physicians



Internists

I see an **internist** primary care physician because he is trained to take care of adults ages 18 and older.



Med-peds physicians

I see a **med-peds physician** because she is trained to take care of both myself and my son. Internists and med-peds physicians may provide routine gynecologic care but **not** pregnancy care.



Family medicine physicians

I see a **family medicine physician** because she is trained to take care of children and adults, and may provide pregnancy care as well as routine gynecologic care.

Working with your parent(s)/legal guardian

Your parent(s)/guardian may have managed much of your care for a long time, so talk to them about what might work for you. Keep in mind that some of these preferences (like the ability to schedule appointments on-line) may be different from how your family has been doing things. As you consider options, you may want to listen in on conversations your caregivers have with providers, insurance companies and pharmacies. That way, as you transition to more self-management, you'll have a better awareness of the types of questions to ask and can think about what works best for you.

What should I remember to bring?



Be sure to bring all of the following items with you to your first appointment:

- Insurance card
- Pharmacy card and prescription bottles
- Phone/calendar for schedules
- Portable medical summary

Your First Appointment

Before the first appointment

Here are some questions to consider asking by phone about the provider and the practice before your first appointment. Think about what works well for your situation. Do you prefer communicating by email? Do you need weekend hours to best fit with work schedules?

- Does this provider accept my insurance?
- How long are first appointments? Follow up appointments?
- Is the practice affiliated with any hospitals? Where can the physician admit patients?
- How does the provider communicate with other providers (electronic medical records, physician portal)?
- Does the provider work with a health care team (nurse case management, social work, nutrition)?
- Are there evening, weekend or same day urgent appointments available?
- When the provider is unavailable, what are the back-up coverage options (phone answering service, on-call availability)?
- Can the practice accommodate special needs (adjustable exam tables, handicapped accessible bathroom)?

At the first appointment

It may take several appointments for your new primary care provider to get to know you and for you to feel comfortable with them. Be sure to keep the following in mind for your first appointment:

- Arrive at least 15 minutes early. There will be paperwork to fill out.
- Bring the insurance card.
- Bring the pharmacy card and all prescription bottles.
- Bring a phone/calendar to schedule a follow up appointment.
- Bring a Portable Medical Summary (see next page).
- **Once you have met your new PCP**, be sure to update your insurance with this info.

Medical Information

What is a portable medical summary?

A Portable Medical Summary is a 2-3 page document that gives an overview of key medical information for new providers. This is especially helpful for first appointments in adult care. They are also very important in the event of an emergency. Portable Medical Summaries can include:

- Current medical problems
- Current medications (prescriptions and over the counter)
- Vaccination List
- Allergies to food or medications
- History of surgeries and past hospitalizations
- Special diets or formulas
- Name/contact information of specialists
- Name/contact information of preferred pharmacy
- Information about durable medical equipment (DME), including type, quantity and supplier
- Insurance type
- Name/contact information of health care proxy

Sharing medical information

When you transfer to adult care, it is important to work with both the pediatric medical team and adult medical team to share information in order to establish a coordinated health care plan with the new providers. It is a good idea to follow these steps:

- Sign a release of medical records for all pediatric providers so medical information can be shared with your new adult provider.
- Request that the adult provider signs up for the Boston Children's Physician Portal, which allows outside providers to access records from Boston Children's.
- Ask for information on how to sign up for the Patient Portal at the adult provider's practice.
- Be aware! If you are still on your parents'/guardians' insurance, they may receive notification of a visit or procedure taking place.

Glossary of Terms

Adult specialist: Provider (doctor) who sees adult patients for specific conditions.

Confidentiality: Confidentiality generally refers to the responsibility of anyone entrusted with your health information to keep that information private. Confidentiality is not required when someone is at risk of hurting themselves or others, or knows of someone being harmed.

Guardianship: Legal way to protect adults who cannot care for themselves by making decisions (including health care decisions) that are in their best interests, or managing their assets.

Health care proxy: Person someone chooses to make decisions for them if they cannot make them for themselves.

Patient portal: Electronic access to a patient's medical record, allowing patients to review records and communicate directly with providers.

Pediatrician: Provider (doctor) who sees children for primary care (preventive care and for illnesses).

Pediatric specialist: Provider (doctor) who sees children for specific conditions.

Portable medical summary: Important summary of medical problems (electronic or on paper) which can be accessed in the Emergency Room or by new physicians as the patient transitions to adult providers.

Protected Health Information (PHI): Written, electronic, or oral health care information with a higher level of privacy protection, requiring written permission to share. Medical records, laboratory reports, and hospital bills are common examples of types of documents that contain PHI.

Provider portal: Electronic access to a patient's medical record, allowing providers outside the hospital to review records.

Release of information: Document that allows providers to share information with others.

Transition: The purposeful, planned process of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems.

Transfer: Move from one provider (pediatric) to another (adult).



Resources

Got Transition?

A website covering all aspects of transition, with information for providers, youth and families.

gottransition.org

Massachusetts Health Care Proxy Form

A clear explanation of the responsibilities of a health care proxy, and simple directions on how fill out and sign the form.

bit.ly/health-care-proxy

Patient Portal

A convenient, easy-to-use and secure way to access your child's health information.

apps.childrenshospital.org/mychildrens

Patient Centered Medical Home

A widely accepted model for how primary care should be organized and delivered throughout the health care system.

pcpcc.org/about/medical-home

Also ask about our other brochures: What Happens When I Turn 18, Young Adult Guide to Health Insurance, and One Step at a Time.