



We recommend parents begin to think about adult life for their child by age 14. Generally speaking, you should consider the following:

- (1) Can my child make decisions as an adult?
- (2) Who will provide services after my child finishes school?
- (3) Who will be my child's health care team?

These are just a few questions, and this all can be stressful to think about. When your child turns 14 you should start asking your child's providers about planning for adult life. These resources may help get the ball rolling. Please bring your questions to clinic visits so our team can help.

### Six Transition Resources

1. [Autism Commission Transition Guide](#): The Autism Commission is a state agency focused on autism-specific resources—they have developed a guide to transition in MA.
2. [Jewish Family and Children's Services](#): Offers support to a wide range of individuals within the metro Boston area.
  - [Disability Life Span Solutions](#): Full range of services designed to support you and your child as they age into adult life (fee-based)
  - [Disability Resource Network](#): Free information, referral, and consultation service. Helping you connect with programs and services that promote the fullest participation in the community.
3. [Federation for Children with Special Needs: The LINK Center](#): connects families, professionals and individuals with disabilities ages 14-26 with information, supports, and services.
4. [Massachusetts Rehabilitation Commission \(MRC\)](#): state government agency that helps individuals with disabilities live and work independently.
  - a. [Family Support Services](#): (ages 16-22) includes technical assistance, training, and individualized transition planning for students and families to help them prepare for life after high school.
5. [Autism Housing Pathways Turning 18 checklist](#): Helpful tool to keep you on the path toward adult life with a focus on housing.
6. [Ability Path](#): Their "Journey to Life After High School" roadmap is a long document, but it covers everything from education to employment and housing, with real stories from individuals with disabilities and their parents.



**Boston  
Children's  
Hospital**

Until every child is well™



# Your Child's Transfer to Adult Providers

A GUIDE FOR PARENTS



### **A note of thanks**

Before going into the details of transition and transfer of care, we must pause and acknowledge you, the parent/caregiver, and your special role of managing the care of a child with chronic medical concerns. We recognize the many hours you have spent scheduling appointments, sorting through insurance paperwork, bringing your child to and from appointments, sitting at the bedside and advocating for your child. Our roles as providers are made possible and worthwhile by your partnership, and we thank you.

It is complicated to think about transition and transfer of care because you and your child may have worked with a health care team for a long time. We acknowledge how important and meaningful this relationship is for your family. It is often just as difficult for us as providers to say goodbye as it is for patients who are moving on to adult medical care. The best “graduation” gift we can give our patients is the chance to make a smooth transfer of care by giving them the tools to make a successful transition. You are so important to making this happen!

We hope you find this guide useful as you prepare your child to take the next steps in life. We are honored to walk alongside you and your family before your young adult starts out on their own path.

# Introduction

## What is transfer of care?

If your child is receiving care at a pediatric hospital like Boston Children's Hospital, their doctor is an expert on kids. When a person becomes an adult, they move from a pediatric doctor to an adult doctor. We call this transfer to adult care.

## Why does my child's care need to be transferred?

The goal is for your child to always be seen by the doctors that can best help them at their developmental stage. Many primary care and specialty doctors who see children (pediatricians) are not trained to care for adults.

When your child reaches adulthood, it may be best for your child to be seen by doctors who are experts in providing care to adults. It is important to have the provider managing your child's medical concerns also address topics including sexuality, fertility, 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 process will look different for each family. If your young adult has an intellectual disability, you may become their guardian and continue to manage their medical care while transferring to new providers.

If your young adult is their own guardian, there will be a transfer of responsibilities from you to your child, such as consenting for care. Many of the tasks you have done for years (scheduling appointments, communicating with providers, getting medications refilled) will now be the responsibility of your child. Hopefully, you have been encouraging your child to be more independent throughout their adolescence.

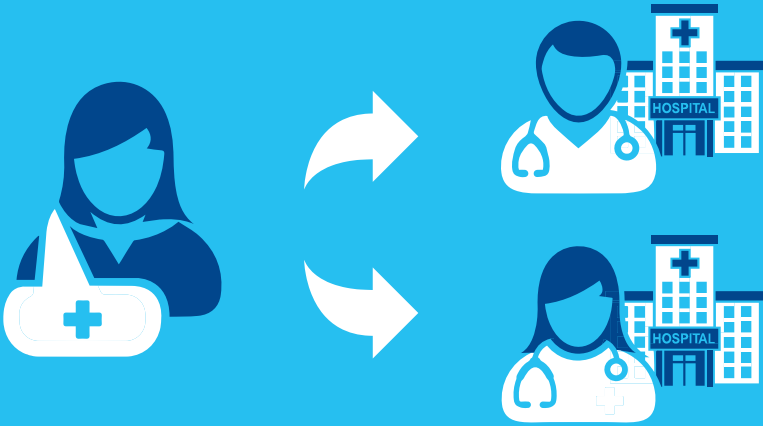
## How should transferring care begin?

During the transition process, it is best to take small steps to slowly increase your child's independence so they can start to manage their own health needs. Taking on too much too fast can get overwhelming for them and for you. The best way to have a smooth transfer of care is to do it slowly enough and with planning so that care is not disrupted.

In **pediatric care**, you can typically see all of your child's specialists at one location, often in one appointment. Your child's specialists may provide care coordination without needing to involve your child's pediatrician.



In **adult care**, you typically have to schedule multiple appointments to see multiple specialists. They may be at different locations. Much of the care coordination is done by your primary care physician.



# What's the difference?

## How is pediatric care different from adult care?

When transferring to adult care, patients may see fewer specialty physicians because the primary care physician can manage many chronic health conditions. This means that the role of the primary care physician has increased in importance. Encourage your child to speak up and advocate for themselves as they partner with their new primary care physician to talk about their care needs.



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 physician (PCP).



Care Model

**Pediatric care** uses a family-centered model.

**Adult care** follows 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 physicians** 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.

# Primary Care Physician

## Who finds the new primary care physician?

If you are, or are going to be, your child's legal guardian, you will be in charge of finding a primary care physician and adult specialists. If your child is going to be their own guardian, they are ultimately responsible for finding them. You may want to guide your child to ask their health care team questions about transferring to adult providers during their pediatric appointments.

## Your child's preferences

If your child is their own guardian, it is important to have a conversation about their preferences and priorities when deciding on a new provider and medical practice. Keep in mind that some of these preferences (like the ability to schedule appointments online) may be different from yours. If your child is their own guardian, they will be the ones to schedule (and keep!) their own appointments. You may want to ask your child to listen in on conversations with providers, insurance companies and pharmacies as they begin this process so they develop an awareness of the types of questions to ask.

## How to find a primary care physician

**Ask your child's pediatrician** for recommendations for adult primary care providers.

**Ask your insurance company** for recommendations of practices accepting new patients.

**Consider inviting your child** to see the same doctor who takes care of your own health.

## Different types of primary care physicians



**Internists** are trained to take care of adults ages 18 and older.



**Med-peds physicians** are trained to take care of both children and adults.



**Family medicine physicians** are trained to take care of children and adults.

Internists and med-peds physicians may provide routine gynecologic care but not pregnancy care. Family medicine physicians may provide pregnancy care as well as routine gynecologic care.

# Adult Specialists

## How to find an adult specialist

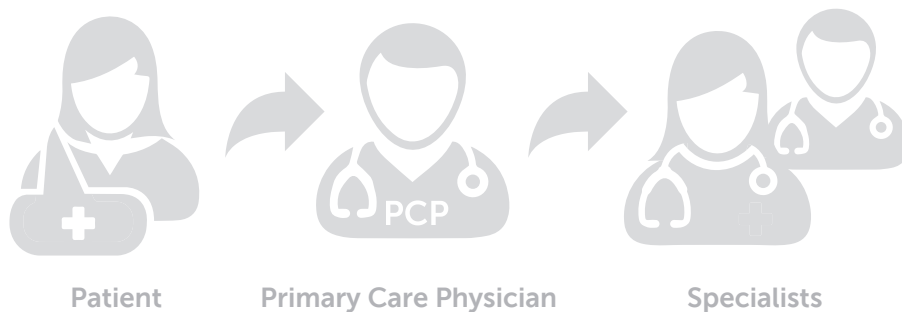
**Ask your child's pediatric specialist** for recommendations for adult specialists.

**Ask your child's insurance company** for recommendations for adult specialists accepting new patients.

If there is a national organization for your child's 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 some patients with rare medical conditions. It is important to communicate early and often with your child's pediatric specialists as you start to look for adult specialists. There may be a period of time when your child sees both pediatric and adult specialists as part of a slow transfer process.



Depending on insurance, your child may need to be referred to specialists by their **primary care physician**. Ask your insurance company for more information.





Insurance  
Card

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## ITEMS TO BRING

to your first appointment

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Pharmacy Card and  
Prescription Bottles

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Phone/Calendar for  
Schedules

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Guardianship Decree  
(if applicable)

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Portable Medical  
Summary

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# The First Appointment

## Before the first appointment

Here are some questions to consider asking about the provider and the practice by phone before the first appointment. Think about what works well for your child's situation. Do they prefer communicating with doctors by email? Does your child need weekend appointments to fit with work schedules?

- 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 took a while for you to establish pediatric health care team that you were comfortable with and that fully understood your child's medical conditions and goals of care. Similarly, it may take several appointments for your child's new primary care provider to get to know them. If you are your child's legal guardian, be sure to keep the following in mind for the first appointment. If your child will be going alone, you may want to remind them to:

- 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 for details).
- Bring a copy of guardianship decree (if applicable).
- Bring an open mind.

# 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
- Name/ contact information of legal guardian, including copy of guardianship order, if applicable

## Sharing medical information

When your child transfers to adult care, it is important to work with both the pediatric medical team and adult medical team to share information to establish a coordinated health care plan with the new providers. If you are your child's guardian, be sure to carry a copy of the guardianship decree for all new appointments, and follow the steps below. If your child is their own guardian, you can encourage them to take the steps below:

- Sign a release of medical records for all pediatric providers so medical information can be shared with 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.

# Glossary of Terms

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

**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

**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)



## **Boston Children's Hospital** Social Work Department Transition Committee

### **Resources**

#### **Got Transition?**

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

[\*\*gottransition.org\*\*](http://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\*\*](http://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\*\*](http://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\*\*](http://pcpcc.org/about/medical-home)

*Also ask about our "What Happens When My Child Turns 18" and "Parents' Guide to Health Insurance" brochures.*