

Transition to Adult Health Care

Parent/Youth Guidelines

In the medical world the term “transition” refers to preparing youth for the experience of becoming consumers of adult healthcare. During childhood, parents take responsibility for seeing that their son or daughter’s medical needs are met—they call for doctor appointments, fill out forms, and keep track of medications. As youth get older, the ability to manage their own medical needs becomes increasingly important. Healthcare transition focuses on building independent health care skills – including self-advocacy, preparing for the adult model of care, and transferring to new providers. Transition planning happens in more than one setting and youth with disabilities and chronic conditions or special health care needs may have several providers partnering with you on transitioning to adult healthcare teams. Our professional staff can help plan and support the transition from pediatric to adult health care. Although physicians may not have the time to participate in IEP meetings, you can bring their recommendations to the school IEP team to make sure health and medical goals are reflected in your youth’s IEP.

There are three initial questions parents should consider to ensure the transition a new provider goes smoothly.

1. Find out the policies regarding the age limits for your child's pediatric/adolescent practice.
2. Ask your employer what their policy is regarding the age limit of coverage.
3. If you have concerns about your son or daughter’s ability to make good decisions about their medical care based on their unique health needs, find out about your state's requirements for guardianship.

This information will provide you with the time frame you need to work within.

Working with Your Pediatrician

Doctors who actively participate in the transition process by suggesting health and medical goals to address in the IEP, coordinating the transition to other providers or clinicians, communicating with appropriate community services (e.g. Medicaid and Social Security), or providing their input on other postsecondary goals significantly improve the transition process for their young adult patients and their families. However, while most providers encourage their adolescent patients with special health care needs to assume responsibility for their own health, far fewer are discussing other important elements of health care transition—including the transfer to an adult provider and insurance continuity and coverage.

Parents can help physicians play a more effective role in the transition to adult health care. Introduce the idea of health care transition to your son or daughter’s pediatric health care primary care provider early in adolescence (age 12 to 14). You can start the discussion by asking the provider: *What do you feel your role is in health care transition planning?*

If the physician is not familiar with recommended practices, refer him or her to resources of GotTransition.org, or your state’s **Family-to-Family Health Information Center**. By beginning the conversation you have begun a partnership that you can build upon in future visits.

Ask about would the possibility of overlapping adult and pediatric care for your son or daughter for a period of time with his or her pediatrician. This approach may be especially helpful if multiple specialists are involved.

Finding an Adult Health Care Provider

How do you find a doctor who will meet your son or daughter’s medical needs, that will be covered by your health plan, and who will give you the care you are looking for?

Before you start looking for a new primary doctor, think about what is most important to your youth:

- Is where the office located important? How will he or she get there? Will you if you will provide transportation – are you willing to travel that far? Does your son or daughter use public transportation? Is the doctor’s office on or near a bus line or subway stop?

- Does he or she need an office that is fully wheelchair accessible, not just the entrance but the accessible examination rooms, X-ray machines, scale, etc.?
- What hospital do you want to use, and is this doctor on the staff there?
- Is it important that a new primary doctor be knowledgeable about your son or daughter's special health care needs? Or is the doctor affiliated with others who have this kind of experience?
- Will your new doctor or clinic help coordinate a patient's care with needed medical specialists?

Gather Recommendations

Ask others for their recommendations of doctors that you can consider. Ask your current doctor, family members, and adults who have health needs similar to your son or daughter's who they would recommend. Ask other parents of young adults who have made the transition to adult health care about their experiences.

Will you also need to find new medical specialists such as a neurologist, orthopedist, or gastroenterologist who will communicate with your new primary doctor? Many young adults with disabilities and their families have developed strong relationships with their pediatric medical specialists. Ask your son or daughter's pediatric specialists to help you transition to adult specialists. You can also ask the same individuals listed above about their recommendations for adult specialists.

Once you have a list of prospective adult health care providers. Sit down with your son and daughter and make a plan about how to approach the interview. Some youth will want to assume the leadership for how to proceed with the interview process. Even youth who need significant parental guidance, however, should be involved to the extent they are able in the process of selecting their new health care provider.

Specialty Care

Contact your health plan or use the website to obtain a list of "In Network Providers" Your health plan may also offer support to help you navigate your options. Insurance case managers are experts at maximizing your benefits and can help you resolve insurance and access issues. Our Care Management staff can help you to use the customer service phone number to inquire.

- Once an Adult Primary Care Provider has been established, ask for a referral
- Look at websites to find Specialty Providers
 - o American Academy of Orthopedic Surgeons
 - o American Academy of Family Physicians
 - o American College of Physicians-Internal Medicine
 - o American Academy of Physical Medicine and Rehabilitation. You may not have seen this type of Physician at Shriners, but may be referred to receive follow-up care from an Adult Physiatrist. A physiatrist is a physician specializing in physical medicine and rehabilitation, including musculoskeletal and neurological problems. Most have expertise in assuming care for young adults with Special healthcare needs and support a journey to optimal independence. Contact your health plan to ask for a list of "In Network Providers"

Interview Potential Doctors

Once you have a gathered a list of potential doctors, sit down with your son or daughter and make a list together of questions that you want to ask each one:

- Does the doctor currently see patients with health conditions similar to yours?
- Is he or she willing to spend time with your son or daughter's pediatrician/adolescent health care provider to gain an understanding of your youth's unique health issues?
- Do office visits include a time for youth to talk about their concerns? (Or you, if you are your son or daughter's guardian and you are overseeing his or her medical care.)
- Can you talk with the doctor directly on the phone? Does the doctor respond to patient e-mail? Do they offer Telehealth visits?
- Does the doctor or their staff help coordinate patient-care with medical specialists?

When you call to actually schedule an interview:

- Double-check with the office to be sure that the doctor works with patients who have your youth's insurance coverage.
- Ask the office if whether or not the doctor is accepting new patients.
- Ask if the office is accessible – the exam rooms, scale and diagnostic equipment such as X-rays as well as the entrance, lobby and parking lot?
- Ask what hospitals the doctor schedules procedures at.
- Ask if the doctor can be reached after hours, or if there is an affiliated urgent care clinic.
- Where do they do tests like lab tests, X-rays or CT scans?
- Do they have social workers or psychologists?
- Are other medical specialists in the same building?
- Do they offer virtual visits?

After the Interview

After you have met with your prospective doctors, discuss the interview with your son or daughter.

- Did the doctor listen to you and your youth's questions?
- Did he or she take enough time to answer your questions?
- Did the doctor explain information in a way that your youth could understand it?
- Did the doctor treat your son or daughter with respect?
- Did the doctor focus his or her attention primarily on the youth rather than on you, the parent?
- Did the doctor discuss topics that are age and developmentally appropriate beyond the youth's special health care needs?
- How comfortable was the transportation time needed to get to the office?
- Was the building accessible in ways that meet your son or daughter needs?

Preparing

It is very important for teens to learn to manage their health conditions or disabilities so that they do not get worse or cause more problems. Typically during the young person's lifetime, the family takes care of planning everything. As an adult, this responsibility falls to them, unless you guardianship is established. Practicing, talking and learning helps them to be able to manage their own healthcare independently, and builds a sense of confidence.

- Let your young person spend time alone with his or her health care providers
- Prepare them for the questions they will need to answer
 - o Chief complaint or concern" - why you came to see the doctor or nurse practitioner TODAY
 - o Current medications and treatments
 - o Past medical history - practice giving your medical history in 3 minutes
 - o Brief review of current information related to your health condition (what's new, how are you feeling, worries)
 - o Problems/concerns that you would like to talk about at a future visit if there is not time today
 - o Resources you need (equipment, supplies, services)
 - o Emotional wellbeing or feelings you may be experiencing
- Encourage increasing self care, independence and responsibility for health matters
- Help them to understand his or her health condition

- Connect them with other young people who are successfully managing their own healthcare
- Demonstrate to them how to keep health records
- Plan for emergencies and disasters, don't wait for an impending storm.
- Explore health insurance options during the transition years
- Talk about what do you need to know and do to manage your health condition at home, in school, at work, and places out in the community with friends
- Adult healthcare providers expect your young adult and not your family, to do the talking unless someone in your family becomes your legal guardian. PRACTICE this early and often.
- Teach them how to follow-through on the plan of care, allow them to make follow-up appointments, get prescriptions, filled and navigate insurance coverage questions. Encourage them to reschedule missed
- Adult healthcare providers expect your young adult and not your family, to do the talking unless someone in your family becomes your legal guardian. PRACTICE this early and often.
- Teach them how to follow-through on the plan of care, allow them to make follow-up appointments, get prescriptions, filled and navigate insurance coverage questions. Encourage them to reschedule missed appointments and notify providers of cancellations.
- Talk to them frequently about healthy habits, such as eating right, exercising, not smoking or chewing, not drinking, and not taking drugs.
- Ask questions about:
 - o The plan of care that your doctor or nurse practitioner recommends (medicines, labs, therapies, routines). Why this is the best plan of action? What to do next, who will do it, and when.
 - o Anything which is unclear, use words like
 - Please tell me more about that.
 - Could you write that down for me?
 - Where can I find more information about this?
 - Is there something you can give me to read?
- Encourage and praise them for SPEAKING UP!



For more information visit shrinerschildrens.org

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