

# Health Care Transition for Parents & Caregivers

## Why is Health Care Transition So Important?

Health care transition is the process of graduating from pediatric medical providers to adult medical providers, with the ultimate goal of the patient managing their own health care. Participating in the health care transition process empowers young people to self-advocate and become active members of their care team while allowing ample time to practice real-world skills before “leaving the nest.”

Research shows that teens and young adults who had a transition between pediatric and adult medicine had higher rates of readiness in managing their care in the adult health system and received a higher quality of care and had better overall experiences due to their engagement in the health system. Hopefully, this period of purposeful engagement in one’s health care also supports higher rates of medication and treatment compliance and prevents unnecessary health complications in early adulthood.

## Why Should Parents and Caregivers Participate in the Health Care Transition Process?

As parents or caregivers of children/teens with diagnosed conditions, you hold the key to a successful health care transition. You remember every illness, emergency department visit, diagnostic test, procedure/surgery, and inpatient stay. You have had access to their medical records, insurance claims, and patient portals their entire lives. Your wealth of knowledge now needs to be transferred to your child, the patient, so they can successfully manage their health care into adulthood without “falling through the cracks.”

## What Can Parents and Caregivers Do at Home to Initiate the Health Care Transition Process?

Although most medical providers will consider health care transition a specific period beginning in a patient’s tween/early teen years, there are so many activities you can do at home that will support your child’s health care transition. Some of these activities can (and should) start long before the “official” health care transition period.

- Medical play at home is a fantastic bridge to clinic, pre-op, and inpatient visits for all ages of children. Parents and caregivers can be wonderful Child Life Specialists, helping children ease into the reality of their medical condition and treatment. Check out these DIY instructions for a pre-op medical play kit.
- Talk out loud! Explain what you are doing (calling the doctor to make an appointment, putting a bandaid on a paper cut, washing your hands to get rid of germs, etc.) to your child in developmentally appropriate terms. Children hear everything and the more adults discuss health-related topics, the more accepted that language becomes.

# Health Care Transition for Parents & Caregivers

- No matter how mundane, parents should involve their children in administrative health tasks. Need to request a prescription refill? Let your child sit next to you and listen in on the call. Toddlers and younger children can color a picture of their medicine bottle while the parent is on the phone. Older children can provide their name and date of birth to the parent. Pre-teens can provide their information plus the name of their medication to the parent. Teens may be ready to make the call with a supportive parent next to them for quick help when asked. Children of all ages can provide their names and insurance cards to the receptionist during a medical visit check-in. These simple ways of including the patient at an early age set expectations that one day this will be their responsibility.
- Encourage patients of all ages to prepare three questions to ask the physician during the appointment. For younger children, they can be fun or of a personal nature (what is your favorite food?), as the goal is to encourage a relationship between the patient and provider. Older children and teens can incorporate relevant health questions as well as basic updates (the annual wellness exam is an excellent practice field).
- Help teens set up their own accounts and patient portals where State law allows. Examples include physician offices, health systems, insurance plans, the Social Security Administration, and even apps on their smartphone.

## What Can Parents and Caregivers Do When the Child is Not Interested in Health Care Transition Work?

An ounce of prevention is better than a pound of cure. -Benjamin Franklin

Incorporating health-related tasks and skills in developmentally appropriate ways from a very young age is sure to lessen the burden once the child becomes a teen/young adult. But all parents surely have a story about their “best laid plans.”

When a child or teen just has no interest in health care transition work, let it be. This is their body, their health condition, and their health journey. The patient must buy-in for health care transition to work. Take some time off, and then revisit the transition discussion, but with a twist:

- Open, honest, kind, and gentle conversation
- Ask the child/teen about their health-related goals
- Acknowledge stressors in their life that would cause them not to participate in health care transition work (peer relationships/othering, fear or worry about their medical condition, etc.)
- Discuss a division of duties and big picture timeline to ease back into transition work
- Encourage the child/teen to share hesitations with their pediatrician or health advocate

# Health Care Transition for Parents & Caregivers

## What Can Parents and Caregivers Do When the Pediatrician is Not Interested in Health Care Transition Work?

Generally speaking, pediatricians are great transition cheerleaders. For those who seem hesitant, a little education often goes a long way.

At your child's next appointment, bring your favorite printed resource from Got Transition, an organization that supports the patient's specific diagnosis, or your health system. Explain that your child needs time to practice health skills in order to be independent in managing their health as a young adult. Ask the pediatrician for their advice, experience with other adolescent patients, and what they feel the patient needs to learn before adulthood. [This is a great guide.](#)

## How Can a Health Advocate Help with Health Care Transition?

At A+J Patient Advocacy, we believe that every individual with significant, chronic, congenital, or lifelong illness should have a health advocate by their side. Children and teens are no exception!

In collaboration with a child's informed and involved parents, a health advocate can make a positive difference in the participation of the child/teen and medical team. A health advocate serves as a transition guide, keeping the big picture and the patient's goals front and center. And let's be honest, sometimes a child or teen just works better with someone other than their parents (blossoming independence, hooray!).

Please take a moment to read our article about [children and health advocates](#), which was published in the Case Management Society of America's magazine in August 2022.

## Health Care Transition Resources for Parents and Caregivers

Got Transition for Parents & Caregivers

- [Readiness Quiz](#)
- [Preparing for Transition Parent/Caregiver Guide](#)
- [Timeline for Parents & Caregivers](#)
- [Questions to Ask Your Child's Pediatrician About Transition](#)
- [Family Toolkit](#)

A+J Patient Advocacy: Never go to a medical appointment empty handed  
<https://heart4advocacy.com/never-go-to-a-medical-appointment-empty-handed/>

A+J Patient Advocacy: How to interview a physician  
<https://heart4advocacy.com/how-to-interview-a-physician/>

# Health Care Transition for Parents & Caregivers

Health systems are beginning to recognize the importance of providing health care transition services. Many larger systems and those attached to universities or medical schools, have adolescent clinics and health care transition programs. Examples include the BRIDGES Program at Boston Children's Hospital and the Transition to Adulthood Clinic at UC Davis MIND Institute. Ask your providers!

Is your child diagnosed with a specific condition? Check out support groups and other agencies working in that disease space. Often, they have specific health care transition recommendations for patients living with the disease. Examples include the American Lung Association Asthma Transition Steps and Cerebral Palsy Guide's Transition Into Adulthood.

\* \* \* \*

For additional resources on Health Care Transition, please visit  
<https://heart4advocacy.com/tag/health-care-transition/>