

# healthcare transition: a q&a guide for parents

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## 1) What is healthcare transition?

Healthcare transition is the process of moving from the pediatric to adult healthcare setting. This is a process, not a singular event, and it requires intentional planning and preparation. The goal of healthcare transition is to make sure that appropriate healthcare services continue into adulthood in order to maximize an individual's function, quality of life, and potential. Healthcare transition happens for everyone but can be especially challenging for people with special healthcare needs and their families.

## 2) At what age should healthcare transition planning begin?

The American Academy of Pediatrics recommends that individuals, families and healthcare teams start planning for transition during the early teen years (generally 12-14 years). While your child might not transfer care to adult healthcare providers for several years, the early teen years are a good time for your child to develop skills needed to independently manage as much of their care as they can. Start by teaching your child about his/her health conditions, medications, and medical care team. If appropriate, you can also allow your child to practice meeting independently with their doctor for a portion of their visits. For a list of other self-management skills, check out [GotTransition.org](http://GotTransition.org).

## 3) Who should be involved in the transition planning process?

Healthcare transition is a team sport that involves the individual, family, and healthcare team. Make a list of people who provide medical services for your child. This medical team may include primary care provider, specialists, therapy providers, nursing

companies, medical equipment providers, and health insurance service coordinators. As your child enters the teen years, start asking each healthcare team member what changes to expect in your child's services as they enter into adulthood.

## 4) At what age do most people move on from their children's hospital team?

Most people transfer care to adult providers between age 18-21, but this is highly dependent on the children's hospital, the medical provider, insurance coverage, and availability of adult specialists. Therefore, it is important to ask each healthcare team member how long they will continue to provide services for your child. Some may continue to provide care into adulthood. This is especially true if a particular medical service/specialty is needed in adulthood but adult providers are not available.

## 5) My child's/My medical history is very complex. How should I get organized for healthcare transition?

A child with medical complexity may have a lengthy medical history that goes back many years. Often, parents have a binder that includes their child's detailed medical history as well as a succinct medical summary (usually 1-3 pages) for the adult healthcare provider to review. You want to provide your adult providers with something they will actually read! If appropriate, you can work on creating a medical summary with your child, as this can be an opportunity for your child to learn about his/her medical history. Review your medical summary with your child's pediatrician and specialist doctors regularly. They can help

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you update it and make sure you include only the relevant details. When your child is ready to transfer care to adult providers, you can send them this medical summary to review prior to your child's first appointment.

What to include in a medical summary:

- Medical diagnoses (examples: Nager syndrome, craniosynostosis, autism, intellectual disability, constipation, g-tube dependence, ADHD, etc): for each diagnosis, include what treatments your child receives for that diagnosis (such as medications, therapies, specific nutrition if applicable) and the name of the doctor that manages the diagnosis
- Surgical history: for each surgery list the date (as best as can remember) and location
- Allergies: to medications and foods
- Medications: up to date list of medications/supplements/vitamins (including dose and frequency)
- Medical Equipment/Supplies: list equipment/supplies as well as the supply company and the doctor that prescribes the equipment
- Support services: list of therapies, home nursing and/or provider services, insurance and waiver case managers
- Communication: Briefly describe how your child communicates (for example: verbal, assistive devices, picture board). You can also include a sentence that highlights his/her strengths!

For sample medical summaries, go to [GotTransition.org](http://GotTransition.org) or [medicalhomeinfo.aap.org/tools-resources/Pages/For-Families.aspx](http://medicalhomeinfo.aap.org/tools-resources/Pages/For-Families.aspx).

## 6) How do I find adult healthcare providers that are suitable for my child's needs?

Putting together an adult healthcare team requires a multi-step approach. First talk to each member of your child's current pediatric medical team (including doctors and support services such as therapy, nursing, and equipment companies) to see how long they will be able to continue to care for your child. You may not need an adult specialist for every pediatric specialist your child sees. An adult primary care doctor can often manage aspects

of your child's care that may have previously been managed by specialists (for example- hypertension, asthma, allergies). Discuss with your child's pediatric specialists whether your child will need an adult specialist in the same field.

Once you know what services your child needs from an adult medical team, there are multiple ways to find adult healthcare providers.

- Ask your pediatric doctors who they recommend for adult care.
- Get involved with local groups (with similar diagnoses) and ask other families who they recommend for adult care.
- Ask your insurance service coordinators to find adult providers in network with your plan. Keep in mind that your child's adult medical team members need to be in network with your child's insurance, which may change as they age.

Finally, if you will need multiple adult doctors, it may be helpful to transition one doctor at a time. It's ok if transferring care to your new adult medical team happens over the course of a few years.

## 7) What legal changes may affect my child's healthcare?

The "age of the majority" is the age at which a minor child becomes an adult. In most states this occurs at age 18 but can be as old as 21 in a few states. As an adult, your child will have the rights and responsibility to make their own decisions, including those regarding medical care. Some young adults can make decisions independently, while others will need varying degrees of support to make decisions. If you think your child will need help making decisions as an adult, discuss this with your pediatric primary care provider before your child turns 18. Recommended options for decision-making support may include guardianship, supported decision-making, power of attorney, or advanced directives. For more information about decision-making support, check out [TheArc.Org](http://TheArc.Org) and [supporteddecisionmaking.org/](http://supporteddecisionmaking.org/).

## 8) How does the transition process affect my child's insurance coverage and other benefits?

Insurance can be complicated and continue to change as your child ages. If your child receives supplemental security income (SSI) and Medicaid services as a minor, be aware that the rules and requirements for adults to receive SSI are different. Therefore, your child's medical condition will be reassessed at age 18 to ensure he/she meets adult disability criteria (which differs from pediatric disability criteria). This review usually occurs in the one-year period beginning on your child's 18th birthday. If your child was not eligible for SSI before age 18 because your household income exceeded the limit, your child may be eligible for SSI at age 18 as only his/her income will be considered. For more information about SSI benefits, go to [ssa.gov/benefits/ssi/](https://ssa.gov/benefits/ssi/).

Medicaid benefits often change at age 21. Before your child turns 21, ask your Medicaid service coordinator what changes to expect. This may include less coverage of therapies, nursing hours, and certain adaptive aids/equipment. If you utilize nursing services, document everything your nursing team does in order to demonstrate continued need for nursing services as your child ages. Before your child's Medicaid program changes at age 21, also verify that the members of your child's adult medical team are in network with your child's future insurance.

Many states have Medicaid waivers that cover equipment and services not covered by Medicaid insurance. In some states, waivers have long waiting lists, so get your child on a waiting list as soon as possible. For more information, go to: [medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html](https://medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html).

Young adults covered by a parent's private health insurance plan can stay on the plan until at least age 26. Depending on your child's abilities and medical complexity, he/she may be eligible to continue on your private health insurance plan past the age of 26 as an "adult disabled

dependent." Contact your employer's human resources department and insurance company well before your child's 26th birthday to discuss this option. Documentation from a physician is often required.

Special needs trusts may also be appropriate for some families. Go to [specialneedsalliance.org](https://specialneedsalliance.org) for more information, including listing of attorneys that specialize in special needs planning.

## 9) In addition to changes in healthcare, what other life transitions should I prepare for?

Transitioning out of high school is a challenging time for all young people and particularly those with special healthcare needs. As young adults age out of school, they may experience loss of their daily routine, socialization with peers, and in-school support services such as therapies. Thankfully, many people with special healthcare needs may continue in high school related programs until age 22. One to two years before completing high school programming, work with your child and school staff to develop a plan for your child after he/she completes school. This may include further schooling, employment, volunteering, social programming, dayhabs, and/or recreational therapy. If your child is interested in post-secondary education, resources are available at [aucd.org/template/page.cfm?id=509](https://aucd.org/template/page.cfm?id=509). Most states have vocational training options for people with disabilities (more information at [askearn.org/state-vocational-rehabilitation-agencies/](https://askearn.org/state-vocational-rehabilitation-agencies/)). Other resources for post-graduation opportunities may include your child's Medicaid/waiver service coordinator or other families with children of similar diagnoses. Having a regular activity and sense of purpose is important for all people and should not end after your child ages out of high school.

During adolescence, your child may also start experiencing changes or ask questions regarding sexual development, special relationships, and/or body image. It is important for all parents to discuss these issues with their children, including

individuals with special healthcare needs. Check out [ncil.org/sex-ed-for-individuals-with-idd/](https://ncil.org/sex-ed-for-individuals-with-idd/) for video-based sexual education resources designed for individuals with intellectual and/or developmental disabilities.

Some young adults may also explore different living options to allow for greater independence, such as a more private space in their current home, a group home, or living independently with provider services or other support services. Talk to other parents for ideas on what may be appropriate for your child. National and local resources on independent living can also be found at [ncil.org](https://ncil.org).

Lastly, if your child needs significant caregiving support throughout adulthood, it is important to start conversations with family members and/or your insurance/waiver service coordinator about who will continue to support and care for your child in the event that you are no longer able. These conversations are challenging but important to have before the need arises.

## 10) What resources are available to help me navigate the transition process?

The healthcare transition process can be overwhelming and daunting, but you don't need to go through it alone! Many local and national resources are available to guide you and your child through this process.

### Local resources:

- Talk to a social worker at your children's hospital or clinic.
- If your child has Medicaid or a Medicaid waiver, ask your assigned service coordinator for help. They can be particularly helpful in looking for in-network adult service providers. Many managed Medicaid plans also provide specialized transition service coordination.
- Get involved with local organizations for families of children with disabilities or chronic illness. Many local organizations provide transition guidance, workshops, and/or mentorship with other families who have gone through the transition process.

### National resources:

- Got Transition ([gottransition.org](https://gottransition.org)) – this is a federal funded national resource center on healthcare transition. Resources are available for youth/young adults, parents/caregivers, and healthcare providers.
- American Academy of Pediatrics' National Resource Center for Patient/Family-Centered Medical Home ([medicalhomeinfo.aap.org/tools-resources/Pages/For-Families.aspx](https://medicalhomeinfo.aap.org/tools-resources/Pages/For-Families.aspx)) – this resource is designed for children and youth with special health care needs and includes a section on "Transition to Adult Care."
- The Arc ([thearc.org](https://thearc.org)) – The Arc is the largest national community-based organization advocating for and with people with intellectual and developmental disabilities. Resources related to healthcare transition and a listing of local Arc organizations can be found on The Arc website.

### Final thoughts

Transitions are hard. The thought of leaving your child's pediatric healthcare team may be scary and anxiety provoking. However, this season can be a time to reflect on how your child has grown, developed, and perhaps overcome medical odds. It can also be a time to look ahead to new opportunities and achievements for your child. As you jump (or gingerly step) into this transition process, remember to take it one step at a time, and know that a little planning now can make a way for a brighter future ahead. In the words of President John F. Kennedy, "Change is the law of life. And those who look only to the past or present are certain to miss the future."