

Crossing the Bridge to Adulthood

A Guide for Youth Transitioning to Adult Care



What is transition?

There are many developmental stages that we experience throughout life. Each stage involves a transition. By the time a person has reached the teen years, he or she already has experienced many transitions. Each transition involved learning new skills, developing independence and gaining confidence.

Another transition that every teen experiences is the transition of moving from pediatric to adult health care. This transition often presents new challenges for a teen or young adult with a chronic illness or special needs and their family. Teens need to learn, practice and become confident in the skills they need to manage their own health as best as possible. Families need to learn about the adult services that will help support their teen in the adult world.

Teens and their families often develop strong bonds with the various health care team members over the years. This working relationship often spans many years. They come to depend on and trust these partners. With this long history together, moving on to adult health care may seem uncomfortable. However, it also can be a positive and beneficial experience for a young adult. A few of the benefits of moving on to adult health care include:

- Adult health care providers have more experience with adult health issues and know how to treat adults.
- Teens can take an active role in decision-making and problem-solving.
- Independence may contribute to a stronger self-esteem.

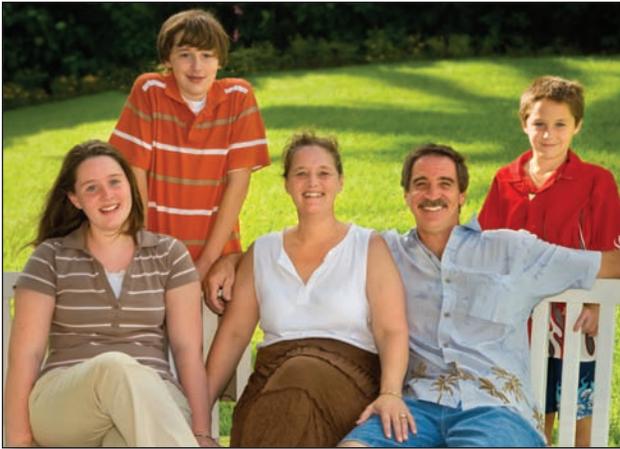
Transition is a process that takes several years. There are skills that teens can begin to learn when they are young which can lead to greater independence as an adult. It is recommended that teens, families and providers work together toward a smooth transition by starting to discuss this topic early. Working together as a team will promote the best possible outcome during the transition process. Although transition to adult health care is one part of the transition process, there are other transition issues that teens need to address during the process. These include:

- Adult services.
- Education.
- Employment.
- Finances.
- Transportation.
- Recreation.

Completing tasks in each of these areas will help a teen achieve a successful transition to the adult world.

Through the transition to adult care, it is natural to feel apprehensive about this process. However, there are many resources available to assist you. If you have questions about transitioning to adult care providers, consider asking your doctor, nurse or social worker. The information in this booklet will be a useful starting tool through the transition process.

Roles in the transition team: Adult family members



What can adult family members do to help prepare for transition?

- Around age 8, begin talking to your child about the changes that will happen in clinic. Explain that doctors and nurses will start to ask him or her questions directly. This will allow your child to get comfortable answering questions with the “safety net” of a parent in the room.
- Work with your child at home to take an active role in his or her care. Gently encourage independence, but know that it will take time.
- Around age 14, consider encouraging him or her to see the health care team independently for the majority of the visit. Parents can join in at the end of the visit to review information and ask any questions or voice concerns. This will help your child become independent and form relationships with health care providers. This also can help teach him or her how to form future relationships with the adult care team.
- Speak to other parents with children who have transitioned to an adult care team.
- Remember, parents are not alone. The health care team will be on hand to help with this change.

A family's perspective on transition

Throughout the years, we have helped our daughter with appointments and helped her understand what physicians explained during her visits. We continue to support her, however, it also is important to help her transition to adulthood. As we have seen her mature, it now is time to help her enter this next phase of her life. It will be important for her to understand her condition and share responsibility for her care.

She needs to understand what medications she is on, when to call for refills, who to call when something doesn't seem right and when to schedule appointments. There also are many insurance issues that she will need to manage.

With the proper planning, she should be able to build relationships with adult providers and be able to seamlessly communicate with them.

*- Ranee,
parent of transitioning youth*

Roles in the transition team: The patient

What can the patient do to prepare for transition?

During the transition process, a doctor or nurse will begin to discuss transition on an ongoing basis. The health care provider and social worker will spend private time to address issues that promote a healthy lifestyle for a teen. They will encourage you to become an active member in the transition process. They also will provide education on the disease process, treatment plan and preventive health issues, such as diet, exercise, smoking, drugs, alcohol and sexual behavior. To help prepare for transition, you can:



- Take on more responsibility for your care as you get older.
- Keep a list of medicines, doctors and other health information.
- Learn how to obtain and maintain an appropriate weight through good nutrition.
- Develop a plan for transition with current health care providers.
- Speak to other young adults who have recently transitioned to an adult health care team.
- Make a list of questions to ask future health care practitioners.
- Remember you are not alone. Parents and the pediatric and adult care teams will help with this change.

Roles in the transition team: The health care team

What can the health care team do to help with the transition process?

- Teach the patient about his or her health condition, including the disease process, medicines and how to manage his or her health.
- Provide the patient with time during clinic visits to spend with the health care team alone so that he or she can learn to actively take part in appointments.
- Answer any questions the patient has about health care issues.
- Offer experiences that will help the patient become independent in managing their condition.
- Encourage the patient to come to the clinic prepared to talk about his or her health, medicines and therapies.
- Develop a comprehensive summary of the patient's health history and plan of care for his or her adult care providers.
- Encourage the patient to meet his or her adult care providers. His or her adult care providers can answer questions and ease he or she into that care system.
- Be available to help the patient with the transition to adult care.



Preparing for adult health care

What needs to be in place before the first visit with the adult health care team?

- Have insurance in place and bring the card to the appointment.
- Prepare a comprehensive summary of pediatric medical care.
- Make sure the adult health care team has received the requested records from the pediatric providers.



- Plan transportation to and from the clinic.
- If a guardian is required, make sure that is in place before the appointment.
- Know the symptoms of health problems so those can be communicated. Bring in the Care Notebook and a list of current medicines.

What can be expected at the first appointment with the adult health care team?

- The comprehensive summary and past medical records will be reviewed.
- All prescriptions will need to be obtained from the new physician.
- If there is a legal guardian, you will be asked to bring a copy of the guardianship documentation or power of attorney.

Transitioning to adult care is something that will take place for all teens. Although it may present new challenges and may seem uncomfortable, the pediatric health care team and the new adult health care team are prepared to help teens and their parents through this process.