
Transition to Adulthood

September 2024

Overview

The transition from being a teenager to becoming an adult can be a difficult time as teens graduate from high school, think about college or jobs, and learn how to live more independently. Teens with spina bifida (SB) face many of the same challenges as other teens. They also have extra responsibilities, such as learning to take care of their own health and moving from children's doctors to adult doctors.

Doctors and health experts recommend that families, doctors, and teens with long-term health conditions like SB start talking about this transition around age 14. Transition preparation should happen slowly over time. Teens should take on more responsibility for their care as they are able, with support from family and health care providers.

Some adults with SB may continue to need help with things like using the bathroom, moving around, personal care, and daily activities. This is more common for people with more complex medical needs.

Moving from children's health care to adult health care

The goal of moving from children's health care to adult health care is to help people with SB stay healthy and active throughout their lives. This change should happen without gaps in care. Health care transition should include:

1. **Planning early**
 - o Planning should begin between ages 12 and 14.
 - o This includes making a medical summary, understanding health insurance, and finding adult doctors.
2. **Being flexible**
 - o The timing of the change should depend on the teen's learning, physical abilities, health, and family situation.
3. **Learning adult health care skills**
 - o Teens should learn how to manage their condition, such as skin care, bowel and bladder care, mobility, and shunt safety.
 - o Teens should also learn how to make appointments, understand preventive care, and go to regular doctor and dental visits.

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From School to Work or College

As teens think about graduating from high school and moving to a job or college, it may be helpful to check for learning or thinking needs. If there are gaps in skills or knowledge, testing may help identify supports that are needed.

These evaluations can help with:

- School transition planning
- Individualized Education Plans (IEPs)
- Job training and vocational services

Families can ask their medical provider for referrals to specialists who understand spina bifida.

Moving from Home to Community Living

Teens should be encouraged to learn skills for living in the community. These include:

- Daily skills like grooming, cooking, and cleaning
- More advanced skills like managing money, making medical appointments, and finding community services

Some schools and community programs offer classes that teach independent living skills. Many adults with SB will be able to make their own decisions and live independently. Others may still need help after age 18. The level of support needed depends on the person's physical abilities, learning needs, and health.

Families should talk with their medical team to decide what kind of support is best. Support options may include:

- Help making medical decisions
- Shared decision-making
- Guardianship, if needed

Helpful tools and resources for planning this transition can be found at www.gotttransition.org.

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This information does not constitute medical advice for any individual. As specific cases may vary from the general information presented here, SBA advises readers to consult a qualified medical or other professional on an individual basis.