
Transition to Adulthood

September 2021

Overview

The transition from adolescence to adulthood can be a complicated time as teens begin to navigate the path from high school to higher education or the workplace and leave home to live independently. Teens with spina bifida (SB) face all the same challenges as other teens during the transition to adulthood. People with SB also face additional challenges as they begin to take more responsibility for their own medical care and move from a child- to adult-oriented healthcare system.

The American Academy of Pediatrics recommends that medical providers, families, and teens with chronic medical conditions like SB begin discussing transition when the teens are around age 14. Transition should be a gradual and coordinated process, with the adolescent/young adult taking as much responsibility for the direction of his or her care as possible. Shared responsibility and ongoing support from family and healthcare providers will remain important for many young adults. In general, individuals with higher level lesions and hydrocephalus may require some level of support for bowel and bladder management, mobility, self-care, transfers, and activities of daily living throughout adulthood.

Pediatric to adult health care

According to the national Guidelines for the Care of People with Spina Bifida, “The primary goal of transition from pediatric to adult health care is to maximize lifelong functioning through the provision of quality, developmentally-appropriate health care that continues uninterrupted as the individual moves from adolescence to adulthood” (Spina Bifida Association, 2018: <http://www.spinabifidaassociation.org/guidelines/>).

Health care transition is a process that should include:

1. Transition planning (ideally beginning between ages 12 and 14 and continuing over the next several years) that includes creating a medical summary, identifying insurance coverage plans, and identifying adult providers to assume care prior to the transition;
2. Flexibility regarding transfer timing based on the individual's cognitive development, physical abilities, social and financial situation, and health status; and
3. Preparation for engaging in adult health care and adult responsibilities through planning and coaching during the teen years. Teens can benefit from specific coaching for managing chronic conditions (such as bowel and bladder management, skin care, mobility, shunt safety, etc.) as well as in navigating the health care system, and preventive care (such as regular primary care and dental visits).

School environment to workplace

As adolescents begin to think about high school graduation and transition to the workplace or higher education, it may be helpful to consider neuropsychological assessment to identify cognitive, adaptive, or learning support

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needs if knowledge or skill gaps have been identified. Neuropsychological assessment can provide helpful information related to a child or adolescent's education and employment needs, such as school transition planning as part of an Individualized Educational Plan and vocational rehabilitation services. To obtain referral information for clinical neuropsychologists in your area knowledgeable about SB, speak with your medical provider or visit the American Board of Professional Psychology (ABPP) website to access the [directory of board certified pediatric clinical neuropsychologists across the United States](#).

Making the transition from home to community living

Adolescents should be encouraged to develop independent living skills that relate to community living, including daily activities like grooming, cooking, and housekeeping to more complex skills like managing finances, scheduling medical appointments, and acquiring agency services. Independent living skills courses, offered by many schools and/or agencies, may be helpful to adolescents as they acquire community living skills.

Many individuals with SB will be able to serve as their own guardian and have independent decision making as adults. Others, however, will continue to need more support even after turning 18. The nature of each individual's physical and cognitive disabilities as well as their health status will influence the balance between independence and the need for support. Talking with your medical team during transition planning will assist with determining the most appropriate plan for your adolescent's specific needs.

Supports may include a medical power of attorney, supportive decision-making, or guardianship.

Transition resources and assessment tools 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.