

Effects of spina bigida on different age groups

[Health & Medicine](#), [Disability](#)



EFFECTS OF SPINA BIGIDA ON DIFFERENT AGE GROUPS Individuals who are affected with spina bifida are faced with many difficult challenges. The social factors are different in each age group (newborns to infants, toddlers and preschoolers, school aged children, adolescences, teenagers, and adulthood). Nevertheless, finding resources in your community, knowing what to expect, and planning for the future can help increase confidence in managing spina bifida, enhance quality of life, and assist in meeting the needs of all family. Spina bifida affects the entire family. People who are affected by spina bifida get around in many different ways. This may include walking without any aids or assistance; walking with braces, crutches or walkers; and using wheelchairs. Some people with spina bifida have difficulty picking up the verbal and non-verbal cues necessary for social skills. Some of the areas that might be difficulty for them are talking over differences without getting angry, persistence when facing frustration, taking turns while talking, understanding social rules, demanding immediate attention, and waiting when necessary. However, finding resources, knowing what to expect, and planning for the future can help. No two children with spina bifida are exactly alike. Children's health issues will be different for each child. Some will have issues that are more severe than other children. With the right care, children born with spina bifida will grow up to reach their full potential.

NEWBORNS AND INFANTS In many cases, infants and children with spina bifida require early and frequent hospitalization. This can interrupt normal social development. The challenge is to balance medical needs with the need to let a child develop into a confident, self-sufficient and independent adult. Regular and physical activity is important for all babies,

especially for those with conditions that affect movement. There are numerous ways for babies with spina bifida to be active. Newborns and infants can be active by: * playing with toys, such as activity mats; * enjoy parks and recreation areas; * participating in community programs, such as the Early Intervention Program for Infants and Toddlers with Disabilities, which is a free program in many communities; and * do exercise with physical therapist.

TODDLERS AND PRESCHOOLERS Life with a toddler or preschooler is both fun and challenging. These young children experience huge mental, social, and emotional changes. They have a lot of energy and enthusiasm for exploring and learning about their world and becoming independent. Since developing independence can be particularly trying for children with spina bifida, parents should begin helping their child develop independence early in childhood. The achievements can be measured one by one; building blocks are an effective way to think of them. In the early years, moving about and exploring things with the eyes, mouth and hands are the elements of independence for the toddler. Parents and other caregivers can help them become more active and independent by: * educating the child about his or her body and about spina bifida; * encouraging the child to make choices, for example, have them choose between two items of clothing; * asking the child to assist with daily tasks, such as putting away toys. Children with spina bifida might require extra help at times. It is very critical that children be given the opportunity to fulfill a task before help is given. It is also important that parents give only the help that is needed rather than helping with the entire task. Parents must become skilled at learning the difficult balance between giving the right amount of help to

increase their child's independence and confidence, while simultaneously not giving the child tasks that cannot reasonably be completed—which might decrease their child's confidence. School aged School connects children regularly with the larger world. Friendships become important and physical, social, and mental skills develop quickly during this time. Children who feel good about themselves are more able to resist negative peer pressure and make better choices. Many children with spina bifida do well in school but some can experience difficulties at school. There are children with learning disabilities (water on the brain), struggle with paying attention, work slowly, be restless, or lose things. They also might have difficulty making decisions. There are activities that children can do both at home and at school to help with these problems. These children might struggle with activities which lacks opportunity to socialize with peers. Children with spina bifida have fewer friends and spend less time with peers than typical developing children. Many social difficulties tend to be stable into adulthood.

Fortunately, with the proper medical care, children with spina bifida can lead active and productive lives. Many children with spina bifida are successful in school and many are actively involved in modified sports activities despite their physical challenges. With recent progress in care for these children, their outlook continues to improve. This is a significant time for children to become more responsible and independent. This is also a good time to start exploring potential lifetime interests such as hobbies, music, or sports.

Acquiring independence can be challenging for people affected by spina bifida. It is important to begin working on this process early in childhood.

Physical activity again is important for children of all ages, but especially for

those with conditions that affect movement. For example, they can: * engage in active play with friends; * roll or walk in the neighborhood; * enjoy parks and recreation areas with playgrounds that are accessible for those with disabilities; * attend summer camps and recreational facilities that are accessible for those with disabilities; and * participate in sports activities and teams for people with or those without disabilities. Children with spina bifida often cannot control when they go to the bathroom (incontinence). They also can develop urinary tract infections. It is important to develop a plan for going to the bathroom that works and is as simple as possible. This can lead to increased health, participation, and independence at school and in the home, and avoid embarrassment for children with spina bifida.

ADOLESCENTS AND TEENS Many physical, mental, emotional, and social changes are associated with the adolescent and teen years. Teens and adolescents develop their own personalities and interests and want to become more independent. It is important for the parents and caregivers of adolescents and teens with spina bifida to take effective steps toward making them independent starting in childhood, so that by the time they are older they can develop the necessary skills to help them reach their full potential. Physical activity is important for all teens and adolescents. There are several ways for teens and adolescents with spina bifida to be active. For example, they can: * engage in physical activities with friends; * roll or walk in the neighborhood; * lift weights; * participate in sports activities and on teams for people with and those without disabilities; and * attend summer camps and recreational facilities that are accessible for those with disabilities. **YOUNG ADULT** The transition from adolescence to adulthood can

be a time of progression and success, as well as difficulty. For people with spina bifida, it is specifically vital to begin planning for transitions in childhood so they are able to lead independent lives as adults. Young adults affected by spina bifida can face challenges, such as: * learning to take care of their own health needs; * working or continuing their education; * volunteering; * finding and using transportation; * living outside their parents' home; and * obtaining healthy relationships. Young adults can provide or manage much of their own care. Some instances include: * finding new doctors that care for adults affected by spina bifida; * obtaining medical insurance if they are no longer covered under their parents' health plan; * talking to health care professionals about their condition; * making doctor appointments; * ordering or reordering medications and supplies; * seeking immediate medical help when needed; and * managing their own bathroom plan. There are many ways for people with spina bifida to be active. Such as: * roll or walk in the neighborhood; * lift weights; and * participate in sports activities and teams for people with or those without disabilities.

Transportation is important, young adults need to be able to find and use transportation safely. Many adults with spina bifida have problems that can affect safe driving. They may need a driver rehabilitation evaluation specialist in order to identify if special changes are needed to a car to make it accessible for driving by someone with spina bifida. Adults also can learn to find and use other transportation safely, such as buses and cabs. Being safely mobile in their homes and communities will help adults become more independent. As adults plan for employment, college, or vocational training, they need to find and use transportation safely. Many young adults are still

getting used to their new independence. They may have started working, volunteering, going to college or other training, or living on their own. Nonetheless, continuing to plan for the future is very important. This involves setting goals and how to achieve them. At times, unexpected problems can make life difficult. It is important for them not give up and to keep moving towards their goals, even if their goals sometimes need to be modified, or take longer than planned. Planning now will help adults continue to grow and succeed as they get older. In summary, people with spina bifida will face lifelong medical challenges associated with this disorder, and the emotional and financial effects that the family will endure are overwhelming. In the United States, children born with spina bifida often live long and productive lives, even though they face many challenges. Though individuals reported having a high quality of life, they also described facing challenges and barriers that affect their ability to fully engage in life experiences. Individuals of all ages from birth through young adulthood reported experiencing common physical challenges such as pain, skin break-down, pressure sores, mobility limitations, latex allergy, and difficulties with endurance and balance. Some individuals between the ages of 6 and 18 years reported having scoliosis and breathing difficulties, during a time of rapid growth. As youth reach the teen years through young adulthood, many also reported difficulties with weight gain and concern about sexuality. Although individuals with spina bifida may experience secondary conditions, the role of support has shown to be a large factor that minimizes these challenges. Family support has been reported as a critical component as well as support given to families from outside sources such as friends, relatives, churches

and other community groups. These supports have shown to help reduce secondary complications for individuals with spina bifida as well as ensure that they can participate fully in life activities and experiences. While individuals with spina bifida face many challenges growing up -whether they are social, physical, or academic -remember that the person with spina bifida is first and foremost a person with similar desires, likes, talents, frustrations, and concerns as all people. They will experience the same developmental milestones as all individuals -from saying " NO! " in the toddler years, to becoming more independent and social in the teen years, to thinking about relationships and employment in the adult years. We are privileged to live in a time of positive change and opportunities for people with disabilities. Expectations are changing for the positive to include individuals with disabilities in all facets of community living. Regrettably, change is usually a slow process and many of the physical and attitudinal barriers of society have not kept speed with the new positive expectations.