

## Spina Bifida Guideline

# Mental health guidelines for the care of people with spina bifida

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**Abstract.** Spina bifida's (SB) impact on cognitive, physical, and psychosocial functioning places individuals at risk for mental health concerns. This article discusses the SB Mental Health Guidelines from the 2018 Spina Bifida Association's Fourth Edition of the Guidelines for the Care of People with Spina Bifida and reviews evidence-based directions with the intention of helping individuals with SB achieve optimal mental health throughout the lifespan. Guidelines address clinical questions pertaining to the psychosocial impact of SB on mental health and adaptation, domains of mental health that are affected in individuals with SB, areas of resilience, common maladaptive behaviors that may impact people with SB, and resources or practices that are helpful in mitigating mental health issues in this population. Gaps in the research and future directions are discussed.

Keywords: Spina Bifida, myelomeningocele, neural tube defects, mental health

### 1. Introduction

Spina bifida (SB), with its pervasive impact on cognitive, physical, and psychosocial functioning, places individuals at risk for mental health concerns. In general, children with chronic illnesses and physical disabilities tend to be vulnerable to mental health concerns, including internalizing and externalizing problems, and low self-esteem [1,2]. Some research suggests that children with spina bifida (SB) appear to be particularly at risk for some of these mental health concerns. When compared to both their typically developing peers without SB and to children with other chronic conditions, individuals with SB experience greater internalizing and externalizing symptoms, regardless of age, gender, or lesion level [3,4] and have lower Health-Related Quality of Life (HRQOL) [5–9]. Similarly, young adults with SB, like their younger counterparts, are susceptible to developing depressive symptoms and anxiety [10,11],

but they are less likely than their typically developing peers to engage in risky behaviors (e.g., using alcohol and having multiple sexual partners) [12]. Research has highlighted factors related to resilience and higher quality of life, including positive attitude towards SB [11], future expectations [13], family satisfaction [11], coping [13,14], and hope – in both the parents [15] and individuals with SB [13].

To understand the risk for mental health concerns amongst individuals with SB, it is important to consider the neuropsychological patterns of development, social functioning and quality of life as they contribute to mental health in children. First, in terms of neuropsychological functioning, children with SB tend to score below average on measures of attention and executive functioning [16,17], with hydrocephalus being a particular concern for cognitive impairment [16,17]. These deficits in attention and executive functioning are associated with subsequent internalizing symptoms [18]. Furthermore, these neurocognitive impairments have been shown to mediate the association between SB and difficulties with social adjustment [17].

Social difficulties also contribute to increased risk for mental health concerns amongst individuals with SB.

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Children with SB tend to be more lonely [19], socially immature and passive [20], and they tend to have fewer friends and social contacts outside of school [21]. This population also experiences significant differences in the quality and reciprocation of friendships; for example, they are more likely to rate friendships as closer than their peers perceive the friendships to be [22]. They tend to have a less adaptive interaction style and lower levels of social dominance [23]. These social difficulties have been found to extend into adulthood [20,21]. Youth with SB also exhibit lower levels of sexual maturation, knowledge, and experience [24–26]. They are less likely to date during adolescence [19,27,28] and to have romantic relationships in young adulthood [29] compared to their typically developing peers.

The physical disability aspect of SB is also intimately connected to mental health. Regular physical activity is widely recognized as a key component of good health and is linked to reduced risk of depression and improved quality of life [30]. Children and adults with SB are less active than the general population [31,32]. Limited motor abilities in individuals with SB [33] are associated with lower levels of participation in physical activities and activities of daily living [34,35]. Given the heightened risk for obesity in this population [36–38], health providers often recommend weight loss for youth with SB. Inconsistent guidance on implementation [39] may be connected to greater risk for disordered eating [40]. However, some evidence suggests that weight management interventions that include physical activities are effective in this population [41,42]. Pain is a critical barrier to engagement in physical activity and activities of daily living, and has also been strongly related to depression and anxiety symptoms both in children [43] and young adults [11] with SB. Thus, regular screening of pain in individuals with SB can help reduce barriers to physical activity, as well as identify those at risk for mental health concerns.

Physical activity limitations, combined with motor and processing challenges can delay the development of autonomy and decision-making abilities, which are other crucial aspects of mental health. Children with SB often lag behind their typically developing peers by at least 2 to 5 years in basic self-management and independence behaviors, such as planning activities with peers and dressing themselves appropriately [44]. Decision-making autonomy also seems to lag behind typically developing peers by approximately two years [45]. Youth with SB are more dependent on their parents for guidance and exhibit less behavioral autonomy at home as well as less intrinsic motivation at school [20,21,45].

Mental health concerns may easily interfere with the achievement of important adult developmental milestones. Conversely, the challenge posed by these emerging milestones may also impact mental health. First, the transition from pediatric to adult healthcare poses significant challenges partly due to limited experience with self-management and decision-making, limited community integration, and continued health needs [10]. The reported quality of health tends to decline from adolescence to young adulthood, presumably due to difficulties in navigating the transition to health care for adults with SB [10,46]. Current transitional care services and programs in SB clinics in the United States show limited continuity of care and wide variation in what is offered to patients. Although most clinics report discussing the concept of transition with patients, most do not discuss insurance coverage changes with patients, communicate with adult providers, or discuss sexuality, pregnancy, and reproductive issues with youth [47]. Given the executive function difficulties in this population and evidence that executive dysfunction negatively predicts achievement of developmental milestones and independence, practitioners should be knowledgeable about these deficits and align with parents and caregivers to promote autonomy in youth with SB [48]. Thus, greater attention and support needs to be provided to individuals making this important transition.

Developmental milestones regarding education, vocation, and community participation and engagement are also challenging for this population and have implications for mental health. For example, emerging adults with SB are less likely to go to college than typically developing youth [10,29,48]. With respect to employment, recent studies report rates of full- or part-time employment ranging from 36–48% [5,48], which are significantly lower than those found in typically developing youth and in those with other chronic conditions. Participation in leisure and recreational activities also tends to be low, with over 50% participating in no activities [49]. Studies that examine the employment and community participation of middle-aged adults with SB document a decline in workforce participation over time, particularly among those with high levels of motor impairment and lower educational levels [50,51]. Bowel and bladder incontinence is also associated with unemployment and social isolation among adults with SB [52,53].

Access to mental health services is a critical issue throughout the lifespan for individuals with SB, their parents and other family members. Such services could begin just after birth for parents as they adjust to having

Table 1  
Clinical questions that informed the mental health guidelines

Age group	Clinical questions
0–11 months	1. What parenting interventions can promote mental health for parents and children?
1–18+ years	1. What is the psychosocial impact of having Spina Bifida on mental health and adaptation across the lifespan? 2. Which domains of mental health are most adversely affected in individuals with Spina Bifida and in what areas of mental health are individuals with Spina Bifida most resilient? 3. What are some common maladaptive behaviors that can negatively impact persons with Spina Bifida across the lifespan? 4. What resources or practices are most effective at mitigating mental health issues in this population?

a child with SB. During the school years, counseling for learning and emotional issues can be accessed via the child's IEP or 504 Plan or public or private insurance. Camp programs can also provide emotional support and a context where children and youth can learn independence and self-management skills. Individual psychotherapy by skilled pediatric psychologists and social workers may be needed during adolescence and adulthood for emotional, educational, and vocational issues related to the transition to adulthood. Regional Independence Living Centers can offer peer counseling and referrals to mental health services for adults with SB.

## 2. Guidelines goals and outcomes

The goals of the mental health guidelines were both practical and aspirational. Below are the primary, secondary, and tertiary outcomes for the mental health guidelines.

### *Primary*

1. Achieve optimal mental health throughout the lifespan as evidenced by adaptive psychological, social, and participation outcomes.

### *Secondary*

1. Maximize adaptation across all factors that are predictive of mental health outcomes (including neuropsychological, family, peer, academic, biological, and condition related predictors). Access services and supports across appropriate domains to optimize mental health throughout the lifespan.

### *Tertiary*

1. Maximize self-management, independence, quality of life, and transition-to-adulthood outcomes by addressing mental health challenges.

## 3. Methods

As part of an initiative within the Spina Bifida

Collaborative Care Network, literature review and consensus-building methods were combined to develop and expand the fourth edition of the Guidelines for the Care of People with Spina Bifida ("Guidelines"). Details regarding the full scope and methodology of the development of all of the Guidelines can be found in the methodology paper published by Dicianno and colleagues [54]. These Guidelines were published via the Spina Bifida Association website [55].

A Mental Health working group was formed consisting of a team of clinical and research experts. This group devised a list of "clinical questions," the answers to which provide guidance on how best to care for people with Spina Bifida and achieve the primary, secondary, and tertiary outcomes agreed upon and defined above.

Evidence-based research and consensus methodologies were used to develop these guidelines. Specifically, a systematic review of multiple databases was conducted and the consensus building methodology, One-Text Procedure, was followed to draft and review documents. This working group presented their guidelines at an in-person meeting using the Nominal Group Technique (NGT). The goal of these Guidelines was to not only guide health care providers but also patients and families, so that people with Spina Bifida can enhance their quality of life throughout their lifespan.

## 4. Clinical questions framing the guidelines

Table 1 presents the clinical questions that informed the mental health guidelines.

## 5. Results

Table 2 presents the Mental Health Guidelines developed by the Mental Health Working Group. These Guidelines are organized by age group. For each age group, the Guidelines aim to address pertinent clinical questions relating to the psychosocial impact of having

Table 2  
Mental health guidelines

Age group	Guidelines	Evidence
0–11 months	<ol style="list-style-type: none"> <li>1. Assess family functioning, stressors, and supports; identify strengths; and build on resources and supports that encourage resilience.</li> <li>2. Provide parents with detailed information about Spina Bifida.</li> <li>3. Connect families with contact information of local Spina Bifida Association (SBA) Chapters and community resources.</li> <li>4. Address developmental strengths and concerns through information and support.</li> <li>5. Refer to Early Intervention Services and the American Academy of Pediatrics.</li> <li>6. Assess quality of parent-child attachment.</li> <li>7. Remote effective parenting skills in stimulation, caregiving, and enjoyment of the child to optimize typical child development.</li> <li>8. Screen for postpartum depression and posttraumatic stress disorder.</li> </ol>	<p>See Prenatal Counseling and Neuropsychology Guidelines</p> <p>Clinical consensus as well as [5,9,56]  <a href="http://spinabifidaassociation.org/learn-about-sb/parents/">http://spinabifidaassociation.org/learn-about-sb/parents/</a>  <a href="http://spinabifidaassociation.org/chapters/">http://spinabifidaassociation.org/chapters/</a>  <a href="http://spinabifidaassociation.org/national-resource-directory/">http://spinabifidaassociation.org/national-resource-directory/</a>  <a href="https://www.aap.org/en-us/Pages/Default.aspx">https://www.aap.org/en-us/Pages/Default.aspx</a></p> <p>See Self-Management and Independence, Physical Activity, and Family Functioning Guidelines</p> <p>Clinical consensus as well as [5,56]  <a href="http://spinabifidaassociation.org/chapters/">http://spinabifidaassociation.org/chapters/</a>  <a href="http://spinabifidaassociation.org/learn-about-sb/parents/">http://spinabifidaassociation.org/learn-about-sb/parents/</a></p>
1–2 years, 11 months	<ol style="list-style-type: none"> <li>1. Address developmental concerns and optimize typical child development by building on resilience resources and supports.</li> <li>2. Encourage families to offer developmentally appropriate choices in daily life activities, including such things as picking up toys, cleaning up, and doing imitative housework.</li> <li>3. Encourage developmentally appropriate play and social opportunities.</li> <li>4. Assess parenting skills and provide education on parenting strategies and behavior management techniques as needed.</li> <li>5. Provide additional age appropriate information about Spina Bifida as the child grows.</li> <li>6. Continue participation in early intervention services, as appropriate.</li> <li>7. Consider referrals for parent-to-parent support opportunities.</li> <li>8. Encourage families to participate in SBA and SBA Chapter-related activities and events (e.g., Spina Bifida Education Days, Walk-N-Roll for Spina Bifida, and other activities organized by local Chapters).</li> </ol>	<p>See Family Functioning, Neuropsychology, Guidelines</p> <p>Clinical consensus as well as [5,20,22,57]</p>
3–5 years, 11 months	<ol style="list-style-type: none"> <li>1. Discuss with parents the importance of their child's socialization and developing friendships with their peers and of taking advantage of opportunities for activities [32,33].</li> <li>2. Encourage participation in preschool educational programs.</li> <li>3. Discuss the importance of making and keeping schedules/routines, doing chores, modeling behaviors, and making age-appropriate choices and decisions.</li> <li>4. Assess social and psychological development and identify resources that build on strengths and encourage resilience.</li> <li>5. Refer for social skills training as indicated.</li> <li>6. Include optimization of mental health when developing an Individualized Education Program (IEP, IFSP or 504 Plan).</li> <li>7. Provide additional age-appropriate information about Spina Bifida as the child grows.</li> <li>8. Refer parents to the local school district to begin the process of requesting special education or classroom support (IEP, IFSP, or 504 Plan) needed to optimize their child's participation in school.</li> </ol>	<p>See Physical Activity, Family Functioning, Self Management and Independence, and Neuropsychology Guidelines</p> <p>Clinical consensus as well as [11,20–22,34,35,45,49,57–60]  <a href="http://spinabifidaassociation.org/chapters/">http://spinabifidaassociation.org/chapters/</a>  <a href="http://spinabifidaassociation.org/national-resource-directory/">http://spinabifidaassociation.org/national-resource-directory/</a></p>
6–12 years, 11 months	<ol style="list-style-type: none"> <li>1. Encourage participation in community activities for recreation.</li> <li>2. Promote the development of friendships by helping families to identify social opportunities (e.g., participation in camps, adaptive sports programs/events, Walk-N-Roll for Spina Bifida, Boy and Girl Scouts, church youth groups, YMCA activities, and SBA and SBA Chapter events).</li> <li>3. Assess the child for depression, anxiety, bullying (including cyber bullying), and social participation. Similarly, identify the child's strengths and build on resources that encourage resilience. Initiate individual and family interventions when appropriate.</li> <li>4. Encourage activities and hobbies that improve face-to-face social contact.</li> <li>5. Promote transfer of age-appropriate medical responsibility from parent to child in those who have the requisite abilities and cognitive capacity.</li> <li>6. Discuss the importance of increasing household responsibilities that are appropriately modified to account for mobility and cognitive limitations.</li> <li>7. Refer children with emotional and/or behavioral difficulties for psychological support and counseling. Identify community resources for social and psychological development (e.g., camps, recreation centers, and more).</li> </ol>	

Table 2, continued

Age group	Guidelines	Evidence
6–12 years, 11 months	<ol style="list-style-type: none"> <li>8. Assess the family's relationship with their child's school and encourage parents to be advocates for their children in the school setting.</li> <li>9. Promote the child's independence and choice in social activities. Promote self-care so that the child is able to be independent in social settings.</li> <li>10. Promote appropriate after-school sports and club activities.</li> <li>11. Provide additional age-appropriate information/knowledge about Spina Bifida as the child grows. Begin to include child in clinical decision-making.</li> </ol>	
13–17 years, 11 months	<ol style="list-style-type: none"> <li>12. Promote and encourage participation in community and SBA and SBA Chapter-related activities.               <ol style="list-style-type: none"> <li>1. Assess peer relationships and friendship.</li> <li>2. Assess for at-risk behaviors (alcohol, drug, or tobacco use and unsafe or unprotected sex), and identify areas of strength and build on resources that encourage resilience.</li> <li>3. Screen for depression or anxiety and initiate individual and family interventions when appropriate.</li> <li>4. Provide counseling and/or behavioral support as needed.</li> <li>5. Promote transfer of medical responsibility from parent to child in those who have the requisite abilities and cognitive capacity.</li> <li>6. Refer for social skills training as needed.</li> <li>7. Encourage activities and hobbies that improve face-to-face social contact.</li> <li>8. Provide counseling regarding sexuality, sexual functioning, fertility, and contraception. Focus on sexual safety issues.</li> <li>9. Discuss the safe use of and choices around drugs and alcohol and conduct risk assessment in this domain.</li> <li>10. Discuss the importance of initiating and organizing opportunities for social activities.</li> <li>11. Discuss the relationship between independence and interdependence and mental health.</li> <li>12. Facilitate the child's involvement with a peer role model, such as a teen with Spina Bifida who is of a similar age.</li> <li>13. Provide or refer to opportunities for formal or informal mentoring.</li> <li>14. Encourage the teen to participate in the school's IEP transition team meeting.</li> <li>15. Develop a plan for the teen's transition to independent living, post-secondary education, vocational training, and career interests.</li> </ol> </li> </ol>	See Self-Management and Independence, Sexual Health and Education, and Transition Guidelines Clinical consensus as well as [11,12,20,22,24–26,45,49,57,59]
18+ years	<ol style="list-style-type: none"> <li>16. Develop a plan for transition from pediatric to adult health care.               <ol style="list-style-type: none"> <li>1. Screen for depression or anxiety and initiate interventions when appropriate.</li> <li>2. Continue the transfer of medical responsibilities in young adults with Spina Bifida who have the requisite abilities and cognitive capacity.</li> <li>3. Encourage activities and hobbies that improve face-to-face social contact.</li> <li>4. Encourage ongoing efforts to promote friendship and social intimacy.</li> <li>5. Encourage and promote vocational or occupational goals and pursuits.</li> <li>6. Maintain efforts for good general health promotion and exercise, as well as specialized Spina Bifida care. Optimize health to reduce the risk of obesity and maximize social opportunities and mental health.</li> <li>7. Recommend SBA resources.</li> <li>8. Continue to refine the plan to ease transition from pediatric to adult health care.</li> </ol> </li> </ol>	Physical Activity and Transition Guidelines Clinical consensus as well as [16,17,27,57,60–62] <a href="http://spinabifidaassociation.org/learn-about-sb/adults/">http://spinabifidaassociation.org/learn-about-sb/adults/</a>

SB on mental health and adaptation. They also address the domains of mental health that are most adversely affected in individuals with SB, areas of resilience, common maladaptive behaviors that may negatively impact persons with SB, and resources or practices that are most effective at mitigating mental health issues in this population.

## 6. Discussion

Given the complex array of neuropsychological, cognitive, social, and physical challenges that accompany SB, individuals with SB are at a heightened risk for mental health problems, including higher rates of symptoms of depression and anxiety, decreased quality of life, and lower self-esteem compared to those in the general population and those with other chronic illnesses [3–9].

The Mental Health Guidelines for the Care of People with Spina Bifida strive to provide evidence-based directives with the following desired goals for individuals with SB. Primarily, these guidelines aim to help people with SB achieve optimal mental health throughout the lifespan, assessed by adaptive psychological, social, and participation outcomes. Secondly, these guidelines were developed so that individuals with SB would maximize adaptation across all factors that are predictive of mental health outcomes and access services and support across appropriate domains to optimize mental health throughout the lifespan. Lastly, as a tertiary outcome, these guidelines aimed to help individuals with SB maximize self-management, independence, quality of life, and transition-to-adulthood outcomes by addressing mental health challenges.

Given the wide range of issues connected to mental health, these guidelines are closely connected to other guidelines related to the care of people with Spina Bifida, including Prenatal Counseling, Neuropsychology, Family Functioning, Physical Activity, Self-Management and Independence, Sexual Health and Education, and Transition [55]. They also direct individuals towards a variety of important services, including Early Intervention Services, Individualized Educational Plans, participation in SBA and SBA chapter-related activities and events, as well as other community programs (camps, adaptive sports programs/events, Walk-N-Roll for Spina Bifida, Boy and Girl Scouts, church youth groups, and YMCA activities).

Gaps in the research underscore important areas for continued investigation and development of resources.

Future research should examine what services and supports could be used to mitigate barriers to optimal mental health, and to identify interventions that are available to enhance mental health across the lifespan in individuals with SB. Several services are promoted in these guidelines, including counseling through a child's IEP or 504 plan, camp programs, individual psychotherapy, and peer counseling, to name a few. Evaluation of these interventions would provide greater empirical support for their implementation with individuals with SB. Furthermore, it is unclear what methods have been implemented by providers who care for children and adults with SB with identified mental health diagnoses to guide their transition to adult health care. It is possible the practitioners are engaging in a variety of strategies to coordinate care for these individuals, but research is needed to identify and better understand the effectiveness of these strategies.

Little is known about the relationship between mental health and a variety of important psychosocial constructs in SB care. Specifically, research is needed to examine the links between mental health and self-management, independence, quality of life, and the transition from pediatric to adult healthcare. Individuals with SB also demonstrate remarkable resilience, especially when they have a positive attitude towards their condition, hold ambitious expectations for their future, are satisfied with their family, and exhibit hope and coping, all of which are linked to higher quality of life [11,13–15]. Further research is needed to identify what resilience factors mediate mental health outcomes in children and adults with SB. Such factors can then inform prevention and intervention efforts.

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The Spina Bifida Association has already embarked on a systematic process for reviewing and updating the guidelines. Future guidelines updates will be made available as they are completed.

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#### **Conflict of interest**

The authors have no conflict of interest to report.

#### **References**

- [1] Lavigne JV, Faier-Routman J. Psychological adjustment to pediatric physical disorders: A meta-analytic review. *J Pediatr Psychol.* 1992 Apr; 17(2): 133–57. doi: 10.1093/jpepsy/17.2.133.
- [2] Thompson RJ, Jr, Gustafson KE. *Adaptation to chronic childhood illness.* American Psychological Association; 1996.
- [3] Ammerman RT, Kane VR, Slomka GT, Reigel DH, Franzen MD, Gadow KD. Psychiatric symptomatology and family functioning in children and adolescents with spina bifida. *J Clin Psychol Med Settings.* 1998; 5(4): 449–65.
- [4] Appleton PL, Ellis NC, Minchom PE, Lawson V, Böll V, Jones P. Depressive symptoms and self-concept in young people with spina bifida. *J Pediatr Psychol.* 1997 Oct; 22(5): 707–22. doi: 10.1093/jpepsy/22.5.707.
- [5] Copp AJ, Adzick NS, Chitty LS, Fletcher JM, Holmbeck GN, Shaw GM. Spina bifida. *Nat Rev Dis Primers.* 2015 Apr 30; 1: 15007. doi: 10.1038/nrdp.2015.7.
- [6] Murray CB, Holmbeck GN, Ros AM, Flores DM, Mir SA, Varni JW. A longitudinal examination of health-related quality of life in children and adolescents with spina bifida. *J Pediatr Psychol.* 2015 May; 40(4): 419–30. doi: 10.1093/jpepsy/jsu098.
- [7] Padua L, Rendeli C, Rabini A, Girardi E, Tonali P, Salvaggio E. Health-related quality of life and disability in young patients with spina bifida. *Arch Phys Med Rehabil.* 2002 Oct; 83(10): 1384–8. doi: 10.1053/apmr.2002.34599.
- [8] Rofail D, Maguire L, Kissner M, Colligs A, Abetz-Webb L. Health-related quality of life is compromised in individuals with spina bifida: Results from qualitative and quantitative studies. *Eur J Obstet Gynecol Reprod Biol.* 2014 Oct; 181: 214–22. doi: 10.1016/j.ejogrb.2014.07.048.
- [9] Sawin KJ, Bellin MH. Quality of life in individuals with spina bifida: A research update. *Dev Disabil Res Rev.* 2010; 16(1): 47–59. doi: 10.1002/ddrr.96.
- [10] Bellin MH, Dosa N, Zabel TA, Aparicio E, Dicianno BE, Osteen P. Self-management, satisfaction with family functioning, and the course of psychological symptoms in emerging adults with spina bifida. *J Pediatr Psychol.* Jan-Feb 2013; 38(1): 50–62. doi: 10.1093/jpepsy/jss095.
- [11] Bellin MH, Zabel TA, Dicianno BE, et al. Correlates of depressive and anxiety symptoms in young adults with spina bifida. *J Pediatr Psychol.* 2010 Aug; 35(7): 778–89. doi: 10.1093/jpepsy/jsp094.
- [12] Murray CB, Lennon JM, Devine KA, Holmbeck GN, Klages K, Potthoff LM. The influence of social adjustment on normative and risky health behaviors in emerging adults with spina bifida. *Health Psychol.* 2014 Oct; 33(10): 1153–63. doi: 10.1037/hea0000050.
- [13] Brei TJ, Sawin KJ, Webb T, Others. Testing a model predicting health related quality of life in a multi-site study of adolescents & young adults with spina bifida. Scientific abstracts: the future is now. In: First World Congress on Spina Bifida Research and Care Orlando (FL): Spina Bifida Association. 2009.
- [14] Sawin KJ, Buran CF, Brei TJ, Cashin SE. Individual and family factors associated with health-related quality of life in ado-

- lescents and young adults with spina bifida. *SCI Nurs*. 2007; 23: 1–16.
- [15] Kirpalani HM, Parkin PC, Willan AR, et al. Quality of life in spina bifida: Importance of parental hope. *Arch Dis Child*. 2000 Oct; 83(4): 293–7. doi: 10.1136/adc.83.4.293.
- [16] Iddon JL, Morgan DJR, Loveday C, Sahakian BJ, Pickard JD. Neuropsychological profile of young adults with spina bifida with or without hydrocephalus. *J Neurol Neurosurg Psychiatry*. 2004 Aug; 75(8): 1112–8. doi: 10.1136/jnnp.2003.029058.
- [17] Rose BM, Holmbeck GN. Attention and executive functions in adolescents with spina bifida. *J Pediatr Psychol*. 2007 Sep; 32(8): 983–94. doi: 10.1093/jpepsy/jsm042.
- [18] Lennon JM, Klages KL, Amaro CM, Murray CB, Holmbeck GN. Longitudinal study of neuropsychological functioning and internalizing symptoms in youth with spina bifida: Social competence as a mediator. *J Pediatr Psychol*. 2015 Apr; 40(3): 336–48. doi: 10.1093/jpepsy/jsu075.
- [19] Blum RW, Resnick MD, Nelson R, St Germaine A. Family and peer issues among adolescents with spina bifida and cerebral palsy. *Pediatrics*. 1991 Aug; 88(2): 280–5.
- [20] Holmbeck GN, Westhoven VC, Phillips WS, et al. A multi-method, multi-informant, and multidimensional perspective on psychosocial adjustment in preadolescents with spina bifida. *J Consult Clin Psychol*. 2003 Aug; 71(4): 782–96. doi: 10.1037/0022-006x.71.4.782
- [21] Holmbeck GN, DeLucia C, Essner B, et al. Trajectories of psychosocial adjustment in adolescents with spina bifida: A 6-year, four-wave longitudinal follow-up. *J Consult Clin Psychol*. 2010 Aug; 78(4): 511–25. doi: 10.1037/a0019599.
- [22] Devine KA, Holmbeck GN, Gayes L, Purnell JQ. Friendships of children and adolescents with spina bifida: Social adjustment, social performance, and social skills. *J Pediatr Psychol*. 2012 Mar; 37(2): 220–31. doi: 10.1093/jpepsy/jsr075.
- [23] Holbein CE, Lennon JM, Kolbuck VD, Zebracki K, Roache CR, Holmbeck GN. Observed differences in social behaviors exhibited in peer interactions between youth with spina bifida and their peers: Neuropsychological correlates. *J Pediatr Psychol*. 2015 Apr; 40(3): 320–35. doi: 10.1093/jpepsy/jsu101.
- [24] Gatti C, Del Rossi C, Ferrari A, Casolari E, Casadio G, Scire G. Predictors of successful sexual partnering of adults with spina bifida. *J Urol*. 2009 Oct; 182(4 Suppl): 1911–6. doi: 10.1016/j.juro.2009.02.065.
- [25] von Linstow ME, Biering-Sorensen I, Liebach A, et al. Spina bifida and sexuality. *J Rehabil Med*. 2014 Oct; 46(9): 891–7. doi: 10.2340/16501977-1863.
- [26] Visconti D, Noia G, Triarico S, et al. Sexuality, pre-conception counseling and urological management of pregnancy for young women with spina bifida. *Eur J Obstet Gynecol Reprod Biol*. 2012 Aug; 163(2): 129–33. doi: 10.1016/j.ejogrb.2012.04.003.
- [27] Friedman D, Holmbeck GN, DeLucia C, Jandasek B, Zebracki K. Trajectories of autonomy development across the adolescent transition in children with spina bifida. *Rehabil Psychol*. 2009 Feb; 54(1): 16–27. doi: 10.1037/a0014279.
- [28] Holmbeck GN, Coakley RM, Hommeyer JS, Shapera WH, Westhoven VC. Observed and perceived dyadic and systemic functioning in families of preadolescents with spina bifida. *J Pediatr Psychol*. 2002 Mar; 27(2): 177–89. doi: 10.1093/jpepsy/27.2.177.
- [29] Cope H, McMahon K, Heise E, et al. Outcome and life satisfaction of adults with myelomeningocele. *Disabil Health J*. 2013 Jul; 6(3): 236–43. doi: 10.1016/j.dhjo.2012.12.003.
- [30] Piercy KL, Troiano RP. Physical activity guidelines for Americans from the US department of health and human services. *Circ Cardiovasc Qual Outcomes*. 2018 Nov; 11(11): e005263. doi: 10.1161/CIRCOUTCOMES.118.005263.
- [31] van den Berg-Emons HJ, Bussmann JB, Brobbel AS, Roebroek ME, van Meeteren J, Stam HJ. Everyday physical activity in adolescents and young adults with meningomyelocele as measured with a novel activity monitor. *J Pediatr*. 2001 Dec; 139(6): 880–6. doi: 10.1067/mpd.2001.119991.
- [32] van den Berg-Emons HJG, Bussmann JBJ, Meyerink HJ, Roebroek ME, Stam HJ. Body fat, fitness and level of everyday physical activity in adolescents and young adults with meningomyelocele. *J Rehabil Med*. 2003 Nov; 35(6): 271–5. doi: 10.1080/16501970310012400.
- [33] Peny-Dahlstrand M, Åhlander A-C, Krumlinde-Sundholm L, Gosman-Hedström G. Quality of performance of everyday activities in children with spina bifida: A population-based study. *Acta Paediatr*. 2009 Oct; 98(10): 1674–9. doi: 10.1111/j.1651-2227.2009.01410.x.
- [34] Buffart LM, van den Berg-Emons RJG, van Meeteren J, Stam HJ, Roebroek ME. Lifestyle, participation, and health-related quality of life in adolescents and young adults with myelomeningocele. *Dev Med Child Neurol*. 2009 Nov; 51(11): 886–94. doi: 10.1111/j.1469-8749.2009.03293.x.
- [35] Marques A, Maldonado I, Peralta M, Santos S. Exploring psychosocial correlates of physical activity among children and adolescents with spina bifida. *Disabil Health J*. 2015 Jan; 8(1): 123–9. doi: 10.1016/j.dhjo.2014.06.008.
- [36] Polfuss M, Bandini LG, Sawin KJ. Obesity prevention for individuals with spina bifida. *Curr Obes Rep*. 2017 Jun; 6(2): 116–126. doi: 10.1007/s13679-017-0254-y.
- [37] Agopian AJ, Canfield MA, Olney RS, et al. Spina bifida subtypes and sub-phenotypes by maternal race/ethnicity in the national birth defects prevention study. *Am J Med Genet A*. 2012 Jan; 158A(1): 109–15. doi: 10.1002/ajmg.a.34383.
- [38] Dosa NP, Foley JT, Eckrich M, Woodall-Ruff D, Liptak GS. Obesity across the lifespan among persons with spina bifida. *Disabil Rehabil*. 2009; 31(11): 914–20. doi: 10.1080/09638280802356476.
- [39] Liu JS, Dong C, Vo AX, et al. Obesity and anthropometry in spina bifida: What is the best measure. *J Spinal Cord Med*. 2018 Jan; 41(1): 55–62. doi: 10.1080/10790268.2016.1195071.
- [40] Stiles-Shields C, Holmbeck GN. Health behaviors and disordered eating in adolescents and young adults with spina bifida: results from a national survey. *Disabil Rehabil*. 2019 Apr 12; 1–7. doi: 10.1080/09638288.2019.1575483.
- [41] Rimmer JH, Wang E, Pellegrini CA, Lullo C, Gerber BS. Telehealth weight management intervention for adults with physical disabilities: A randomized controlled trial. *Am J Phys Med Rehabil*. 2013 Dec; 92(12): 1084–94. doi: 10.1097/PHM.0b013e31829e780e.
- [42] Stiles-Shields C, Crowe AN, Bechtel Driscoll CF, et al. A systematic review of behavioral intervention technologies for youth with chronic health conditions and physical and intellectual disabilities: Implications for adolescents and young adults with spina bifida. *J Pediatr Psychol*. 2019 Apr 1; 44(3): 349–362. doi: 10.1093/jpepsy/jsy097.
- [43] Oddson BE, Clancy CA, McGrath PJ. The role of pain in reduced quality of life and depressive symptomatology in children with spina bifida. *Clin J Pain*. Nov-Dec 2006; 22(9): 784–9. doi: 10.1097/01.ajp.0000210929.43192.5d.
- [44] Davis BE, Shurtleff DB, Walker WO, Seidel KD, Duguay S. Acquisition of autonomy skills in adolescents with myelomeningocele. *Dev Med Child Neurol*. 2006 Apr; 48(4): 253–8. doi: 10.1017/S0012162206000569.

- [45] Devine KA, Wasserman RM, Gershenson LS, Holmbeck GN, Essner BS. Mother-adolescent agreement regarding decision-making autonomy: A longitudinal comparison of families of adolescents with and without spina bifida. *J Pediatr Psychol*. 2011 Apr; 36(3): 277–88. doi: 10.1093/jpepsy/jsq093.
- [46] Cox A, Breau L, Connor L, McNeely PD, Anderson PA, MacLellan DL. Transition of care to an adult spina bifida clinic: Patient perspectives and medical outcomes. *J Urol*. 2011 Oct; 186(4 Suppl): 1590–4. doi: 10.1016/j.juro.2011.04.011.
- [47] Kelly MS, Thibadeau J, Struwe S, Ramen L, Ouyang L, Routh J. Evaluation of spina bifida transitional care practices in the United States. *J Pediatr Rehabil Med*. 2017 Dec 11; 10(3–4): 275–281. doi: 10.3233/PRM-170455.
- [48] Zukerman JM, Devine KA, Holmbeck GN. Adolescent predictors of emerging adulthood milestones in youth with spina bifida. *J Pediatr Psychol*. 2011 Apr; 36(3): 265–76. doi: 10.1093/jpepsy/jsq075.
- [49] Boudos RM, Mukherjee S. Barriers to community participation: Teens and young adults with spina bifida. *J Pediatr Rehabil Med*. 2008; 1(4): 303–10.
- [50] Mahmood D, Dicianno B, Bellin M. Self-management, preventable conditions and assessment of care among young adults with myelomeningocele. *Child Care Health Dev*. 2011 Nov; 37(6): 861–5. doi: 10.1111/j.1365-2214.2011.01299.x.
- [51] Törnblom M, Jonsson U, Sunnerhagen KS. Work participation among middle-aged persons with cerebral palsy or spina bifida – a longitudinal study. *Disabil Health J*. 2014 Apr; 7(2): 251–5. doi: 10.1016/j.dhjo.2013.06.005.
- [52] Wiener JS, Suson KD, Castillo J, et al. Bowel management and continence in adults with spina bifida: Results from the national spina bifida patient registry 2009–15. *J Pediatr Rehabil Med*. 2017 Dec 11; 10(3–4): 335–343. doi: 10.3233/PRM-170466.
- [53] Wiener JS, Suson KD, Castillo J, et al. Bladder management and continence outcomes in adults with spina bifida: Results from the national spina bifida patient registry, 2009 to 2015. *J Urol*. 2018 Jul; 200(1): 187–194. doi: 10.1016/j.juro.2018.02.3101.
- [54] Dicianno BE, Beierwaltes P, Dosa N, et al. Scientific methodology of the development of the guidelines for the care of people with spina bifida: An initiative of the spina bifida association. *Disabil Health J*. 2020 Apr; 13(2): 100816. doi: 10.1016/j.dhjo.2019.06.005.
- [55] Spina Bifida Association. Guidelines for the care of people with spina bifida. 2018. Available at <https://www.spinabifidaassociation.org/guidelines/>.
- [56] Holmbeck GN, Devine KA. Psychosocial and family functioning in spina bifida. *Dev Disabil Res Rev*. 2010; 16(1): 40–6. doi: 10.1002/ddrr.90.
- [57] Barf HA, Post MWM, Verhoef M, Jennekens-Schinkel A, Gooskens RHJM, Prevo AJH. Restrictions in social participation of young adults with spina bifida. *Disabil Rehabil*. 2009; 31(11): 921–7. doi: 10.1080/09638280802358282.
- [58] Buffart LM, van der Ploeg HP, Bauman AE, et al. Sports participation in adolescents and young adults with myelomeningocele and its role in total physical activity behaviour and fitness. *J Rehabil Med*. 2008 Oct; 40(9): 702–8. doi: 10.2340/16501977-0239.
- [59] Greenley RN, Coakley RM, Holmbeck GN, Jandasek B, Wills K. Condition-related knowledge among children with spina bifida: Longitudinal changes and predictors. *J Pediatr Psychol*. 2006 Sep; 31(8): 828–39. doi: 10.1093/jpepsy/jsj097.
- [60] American Academy of Pediatrics, Council on Communications and Media. Media Use in School-Aged Children and Adolescents. *Pediatrics*. 2016 Nov; 138(5): e20162592. doi: 10.1542/peds.2016-2592.
- [61] Wallander JL, Feldman WS, Varni JW. Physical status and psychosocial adjustment in children with spina bifida. *J Pediatr Psychol*. 1989 Mar; 14(1): 89–102. doi: 10.1093/jpepsy/14.1.89.
- [62] Dicianno BE, Kurowski BG, Yang JMJ, et al. Rehabilitation and medical management of the adult with spina bifida. *Am J Phys Med Rehabil*. 2008 Dec; 87(12): 1027–50. doi: 10.1097/PHM.0b013e31818de070.



## Enemeez® & Enemeez® Plus mini-enemas contain a delivered dose of 283 mg of docusate sodium

a solution proven effective for bowel care needs associated with spina bifida, spinal cord injury, traumatic brain injury, stroke, multiple sclerosis and general constipation in patients 12 years and older. A different formulation is available for children 2 to 12 years of age.



Actual Size



**Bowel continence significantly affects quality of life for individuals with spina bifida. Enemeez (docusate sodium) provides a fast, effective and safe bowel management program, reducing time spent on bowel care.**

### Neurogenic Bowel, Constipation & Fecal Incontinence in Spina Bifida Patients

The hallmark clinical presentation is the inability to “voluntarily” control the defecation process or the inability to routinely perform elimination of stool/waste from the body. Patients with Spina Bifida may also experience:

- Constipation, very often severe
- Bowel obstructions, rectal impaction with sensory loss
- Hemorrhoids
- Nausea and vomiting
- Abdominal pain, bloating-distention, cramping, and lethargy – “sluggish feeling”
- Diet changes = decreased appetite - “grazing-snacking”
- Dehydration = electrolyte disturbances and increased UTI risk
- Soiling and unplanned evacuation of stool / social anxiety

### Enemeez® & Enemeez® Plus Mini-Enemas are a Fast, Effective & Safe Solution

- ✓ Fast, predictable results typically in 2-15 minutes.<sup>1</sup>
- ✓ Can assist in reducing time spent with patient for dressing/redressing due to episodes of incontinence or fecal discharge.<sup>2</sup>
- ✓ Can virtually eliminate episodes of incontinence.<sup>3</sup>
- ✓ No mucosal discharge<sup>4</sup>; helps to maintain healthy skin integrity
- ✓ Non-irritating formula. No after-burn.
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- ✓ Enemeez® Plus includes 20mg of benzocaine, assisting in the anesthetization of the rectum & lower bowel. The formulation was developed for patients who experience painful bowel movement.

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