

# Guidelines for the Care of People with Spina Bifida

## Nutrition, Metabolic Syndrome, and Obesity

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### Introduction

Healthy nutrition is important for everyone. Individuals with Spina Bifida experience unique challenges related to healthy dietary intake across the lifespan.<sup>1</sup> During infancy, some babies may experience slow weight gain and inadequate nutrition. This is typically due to a complex interplay of medical and social factors, such as brain stem dysfunction, shunt obstruction, silent aspiration, sleep apnea, recurrent infections, and altered feeding dynamics related to frequent hospitalization and caregiver stress. However, most children with Spina Bifida follow typical growth patterns until they are four years of age. After that, increased fat mass (versus lean mass) has been found when compared with children without Spina Bifida.<sup>2</sup> Children with Spina Bifida who have a latex allergy may limit their intake of fresh fruits and vegetables due to cross-reacting foods (Latex and Latex Allergy in Spina Bifida Guidelines). Those with the Chiari II malformation may have an aversion to textured foods because of brainstem dysfunction.<sup>3</sup> For many individuals with Spina Bifida, concern about bowel and bladder accidents may be prioritized over hydration and optimal nutrition.<sup>4</sup> Poor eating habits can lead to constipation, skin breakdown, osteoporosis, anemia, obesity, metabolic syndrome, and other preventable secondary conditions.<sup>5</sup> It is therefore critical to work with children, families and adults with Spina Bifida to emphasize the importance of healthy nutrition and a balanced diet on overall health and wellness.<sup>6</sup>

Children and adults with Spina Bifida have higher rates of overweight and obesity compared to the general population,<sup>7</sup> which may lead to negative health outcomes later in life such as metabolic syndrome, cardiovascular disease and type II diabetes.<sup>8</sup> Girls with Spina Bifida diagnosed with premature puberty may experience weight gain,<sup>9</sup> especially if pharmacological treatments are used. Polycystic Ovary Syndrome can also lead to weight gain in women with Spina Bifida.<sup>10</sup> Sleep apnea can result from weight gain or result in changes in weight over time.<sup>11</sup> Overweight among people with Spina Bifida may also impact mobility, independence, and quality of life.<sup>12</sup> It is important for people with Spina Bifida to understand the possible risks associated with both poor nutrition and obesity and for health care professionals to discuss these topics using a collaborative, strengths-based approach. (Health Promotion and Preventive Health Care Services Guidelines, Physical Activity Guidelines)

It is recommended that body mass index (BMI) be calculated at clinical encounters in order to track an individual's BMI trajectory and guide discussion of appropriate nutrition and weight management strategies. The appendix accompanying these guidelines summarizes anthropometric measurement techniques that can be used to accurately calculate BMI in people with Spina Bifida.

These guidelines aim to provide the best available evidence for promoting healthy nutrition in people with Spina Bifida across the lifespan. The guidelines will also suggest how health care professionals can have positive weight-related conversations with their patients, and offer strategies to prevent and manage obesity.

## Outcomes

### Primary

1. Maximize and support wellness through the lifespan.

### Secondary

1. Reduce and prevent other secondary conditions related to poor nutrition and overweight/obesity, including metabolic syndrome.

### Tertiary

1. Support the development of client/caregiver knowledge, self-management skills, and self-efficacy related to nutrition and dietary habits.

## 0-11 months

### Clinical Questions

1. What nutritional support should be provided when infants with Spina Bifida first go home from the hospital?
2. What guidance on breastfeeding and/or use of breast milk should be given to parents of infants with Spina Bifida?

### Guidelines

1. Assess weight, height and occipital frontal head circumference at every clinical encounter.<sup>13-14</sup> (Appendix: BMI and Body Composition Measurements)
2. Ensure that the family's nutrition plan is followed closely by a primary care provider:
  - Refer the family to community nursing and other support groups to ensure close monitoring of the child's growth and whether there are issues with feeding and elimination. (clinical consensus)
  - Connect the family with the Spina Bifida specialist clinic nearest them. (clinical consensus)
3. Provide parents and caregivers with pre- and post-natal guidance and support on breastfeeding.
  - Discuss with them that ideally, infants with Spina Bifida should breastfeed or be given breast milk exclusively for the first six months. Infants should continue to have breast milk for a year or more, as with all neonates.<sup>15</sup>
  - Inform the mother that if the spinal surgery precludes immediate breast feeding, she will need to pump breastmilk to feed her baby until it is possible to transfer her baby to her breast.<sup>16</sup>
  - Urge the mother to begin pumping breast milk within six to 12 hours of delivery.
  - Emphasize the need to pump frequently (eight to 10 pumping sessions per 24 hours for the first 7-10 days) to ensure enough will be available once the infant has surgery.<sup>16</sup>
  - Advocate for babies to be hospitalized in close proximity to their mothers to facilitate breastfeeding.<sup>17</sup>
  - Provide mothers with information about accessing breast milk banks and to plan for situations where she cannot provide the breast milk herself.<sup>18</sup>
  - Encourage mothers to nurse their child in a flat position for five days following surgery to reduce pressure on the wound and avoid a cerebral spinal fluid leak.<sup>19</sup>
  - Provide the mother with information about breastfeeding equipment options that can help meet the individual needs of the child with Spina Bifida (e.g., different types of propping pillows, nipples, bottles, pumps, latex-free equipment, and supplemental nursing systems).<sup>19</sup>

- Mention that severe Chiari malformation may affect successful latching and coordination of sucking, swallowing, and breathing. A referral to a lactation consultant should be made if mothers continue to experience challenges.<sup>16</sup>
- Support mothers to thicken their breast milk to prevent aspiration.<sup>20</sup>
- Suggest breastfeeding or non-nutritive sucking (finger or pacifier) as ways to comfort their baby and assist them with pain management for acute procedures such as injections.<sup>21</sup>
- Highlight that the baby's transition from drinking breastmilk to eating solid food can cause constipation.<sup>22</sup>
- Close multi-disciplinary follow up is indicated for infants with slow weight gain and failure to thrive. (clinical consensus)

## 1-2 years 11 months

### Clinical Questions

1. What evidence-based information can be provided to parents on nutrition and obesity prevention and management?
2. What is the best way to manage constipation with diet for this age group?
3. How can providers communicate with parents about the benefits of a healthy diet in an understandable manner?

### Guidelines

1. Assess weight and height at every clinical encounter.<sup>14</sup> (clinical consensus) (Appendix: BMI and Body Composition Measurements)
2. Measure occipital frontal head circumference until two years of age.<sup>13</sup> (Appendix: BMI and Body Composition Measurements)
3. Support families as they work to establish a healthy relationship and behavior towards food with their child. Tailor the advice to the family as appropriate.
  - Start introducing healthy foods as early as possible to get them integrated into food preferences. It may be harder to do so later, when food preferences are more entrenched.<sup>23</sup>
  - Recognize that children with Chiari malformation may have sensitivity to different food textures.<sup>3</sup>
  - Consider that adults and families with lower incomes may experience food insecurity.<sup>1</sup>
  - Caution the parents that habitually providing unhealthy foods can lead to a cycle of more requests and greater consumption of unhealthy foods. In contrast, healthy feeding practices early on can help avoid that cycle.<sup>24</sup>
  - Discuss with parents and caregivers that overly restricting food, especially energy-dense foods that are high in fat and have a low water content such as cookies, chips, and nuts, can lead their child to overeat those foods when they become available.<sup>23</sup> Therefore, balance is needed.
  - Caution parents against using food as a reward or positive reinforcement, which can create an unhealthy relationship with food that is hard to break later on and that may lead to undesirable eating behaviors.<sup>23,25</sup> Provide parents with other strategies for positive reinforcement rewards such as praise, stickers, and small toys. (clinical consensus)
  - Educate families on the importance of consuming a balanced diet and how it affects the whole body.<sup>6</sup>
  - Discuss that some fluid and food options used to help ensure hydration and bladder/bowel function are not necessarily the right choices for weight management (e.g. chocolate milk, juice, and sports beverages). Instead,

encourage them to hydrate by drinking non-caloric fluids (e.g. water, club soda, sugar-free flavored drinks).<sup>26</sup>

4. Speak with parents about nutrition in terms of their child's health and growth.

- Provide regular opportunities for parents to discuss any concerns about their child's weight, growth, and/or eating behaviors.<sup>27</sup> A trusting therapeutic relationship can greatly facilitate an honest and open discussion.<sup>28</sup>
- Partner with parents to identify and address specific challenges that the family is facing.<sup>28</sup>
- Discuss that poor eating habits and reduced activity may lead to obesity, constipation, skin breakdown, osteoporosis, anemia, and other problems.<sup>5</sup> Additionally, mention that children with Spina Bifida have a high risk of obesity because they have less calorie-burning tissue (lean body mass) and a lower rate of burning calories (metabolic rate).<sup>7,29</sup>
- Show parents the trajectory of a child's weight and height (or other measures of growth and adiposity), if appropriate. Use a growth chart as a visual aid, without referring to growth cut-offs developed for typically developing children.<sup>1</sup> A steeply-increasing trajectory would indicate that overweight or obesity may be a concern and warrant proactive discussions of preventative strategies.<sup>28</sup>
- Highlight the importance of parents modeling healthy behaviors themselves to their children from an early age.<sup>23,30-31</sup> Encourage the whole family to get involved in healthy living activities, not just the child with Spina Bifida.<sup>32</sup>
- Discuss that children with Spina Bifida, especially those who are non-ambulatory, who undertake low levels of physical activity, and those with higher body fat levels or contractures, are at increased risk for bone fractures.<sup>33</sup> Encourage physical activity and healthy lifestyles. (Physical Activity Guidelines)

5. Provide guidance on maintaining good bowel health.

- Explain that increased fiber in the child's diet will add bulk to the stool and make it easier to pass. Sources of fiber include fruit, vegetables, and whole meal or whole grain bread and cereals.<sup>5</sup>
- Recommend the same guidelines for daily fiber intake that are recommended for all children:<sup>34</sup>
  - 1-3 years: 19g
  - 4-8 years: 25g
  - 9-13 years: female–26g, male–31g
  - 14-18 years: female–26g, male–38g
- Recommend that if the child is constipated, parents should increase fiber intake slowly over two to three weeks by adding one new high fiber food every two to three days. Increasing fiber too quickly can make the constipation worse or cause gas, cramping, and diarrhea. (clinical consensus)
- Recommend more fluids, especially water and non-caloric fluids, which will also soften the stool and help with constipation. Follow the 24-hour period daily maintenance fluid requirements calculation<sup>35</sup>:
  - 100 mL/kg for the first 10 kg body weight
  - + 50 mL/kg for the next 10 kg body weight
  - + 20 mL for every kilogram of body weight over 20 kg
- Further guidance can be found in the Bowel Function and Care Guidelines.

6. Screening for dyslipidemia (fasting lipid profile) is recommended every two years from two years of age if the child's BMI is above 95th percentile or a family history of dyslipidemia/early cardiovascular disease and/or morbidity in first- or second-degree relatives is present.<sup>36</sup>

## 3-5 years 11 months

### Clinical Questions

1. What evidence-based information on nutrition and obesity prevention and management can be provided to parents?
2. What is the best way to manage constipation with diet for this age group?
3. How can providers communicate with parents about the benefits of a healthy diet in an understandable manner?

### Guidelines

1. Conduct annual assessments of weight, height or arm span, and calculate BMI. (clinical consensus) (Appendix: BMI and Body Composition Measurements)
2. Discuss general weight-management principles with all families of children with Spina Bifida, and highlight the importance of healthy behaviors for the entire household.
  - Provide regular opportunities for parents to discuss concerns with their child's weight, growth and/or eating behaviors.<sup>27</sup> A trusting therapeutic relationship can greatly facilitate an honest and open discussion.<sup>37</sup>
  - Emphasize the broad benefits of healthy eating and physical activity, offering strategies to enable the child to incorporate healthy lifestyle behaviors appropriate to their abilities.<sup>4</sup>
  - Consider that adults and families with lower incomes may experience food insecurity.<sup>1</sup>
  - Highlight that early eating patterns and relationships with food are critical for ongoing good nutrition through the lifespan.<sup>27</sup>
  - Discuss that some fluid and food choices to help ensure hydration and bladder/bowel function are not necessarily the right choices for weight management (e.g. chocolate milk, juice, and sports beverages).<sup>26</sup>
  - Show parents the trajectory of a child's weight and height (or other measures of growth and adiposity). Use a growth chart as a visual aid, without referring to growth cut-offs developed for typically-developing children.<sup>1</sup> A steeply-increasing trajectory would indicate that overweight or obesity may be a concern and warrant proactive discussions of preventative strategies.<sup>28</sup>
  - Discuss with parents, if relevant, that the Body Mass Index (BMI) is an imperfect indicator of health in all young people and especially in children with Spina Bifida due to difficulties measuring height and body composition.<sup>29</sup>
  - Consider monitoring other measures of adiposity, such as waist circumference.<sup>38</sup> (Appendix: BMI and Body Composition Measurements)
  - Explain that most children with Spina Bifida follow typical growth patterns until they are four years of age. After that, increased fat mass (versus lean mass) has been found when compared with children without Spina Bifida.<sup>2</sup>
  - Discuss that linear growth or height will also be slower than peers without Spina Bifida due to paresis or paralysis of lower limbs,<sup>39</sup> which also reduces calorie requirement.
  - Highlight that children with Spina Bifida, especially those who are non-ambulatory, who undertake low levels of physical activity, and who have higher body fat levels or contractures, are at increased risk for bone fractures. Recommend a diet with adequate calcium and vitamin D.<sup>33</sup>
3. Provide guidance on maintaining good bowel health.
  - Explain that increased fiber in the child's diet will add bulk to the stool and make it easier to pass. Sources of fiber include fruit, vegetables, and wholemeal or whole grain bread and cereals.<sup>5</sup>

- Recommend the same guidelines for daily fiber intake that are recommended for all children<sup>34</sup>:
    - 1-3 years: 19g
    - 4-8 years: 25g
    - 9-13 years: female–26g, male–31g
    - 14-18 years: female–26g, male–38g
  - Recommend that if the child is constipated, parents should increase fiber intake slowly over two to three weeks by adding one new high fiber food every two to three days. Increasing fiber too quickly can make the constipation worse or cause gas, cramping, and diarrhea. (clinical consensus)
  - Recommend more fluids, especially water and non-caloric fluids, which will also soften the stool and help with constipation. Follow the 24-hour period daily maintenance fluid requirements calculation:<sup>35</sup>
    - 100 mL/kg for the first 10 kg body weight
    - + 50 mL/kg for the next 10 kg body weight
    - + 20 mL for every kilogram of body weight over 20 kg
  - Further guidance can be found in the Bowel Function and Care Guidelines.
4. Screening for dyslipidemia (fasting lipid profile) is recommended every two years if the child’s BMI is above the 95th percentile or a family history of dyslipidemia/early cardiovascular disease and/or morbidity in first- or second-degree relatives is present.<sup>36</sup>

## 6-12 years 11 months

### Clinical Questions

1. What information do schools and communities need to know about the special dietary and adapted equipment needs of students with Spina Bifida in order to help children eat and access food independently at school or in the community?
2. What parenting strategies can encourage a balanced and healthy diet for the whole family?
3. What is the best way to manage constipation with diet for this age group?
4. Are children with Spina Bifida and obesity at higher risk for metabolic syndrome?
5. Should screening for metabolic complications of obesity be performed in children aged 6-12 years with Spina Bifida?
6. Is there evidence to support the role of weight management intervention in the prevention of metabolic syndrome?

### Guidelines

1. Conduct annual assessment of weight, height or arm span, and BMI. (clinical consensus) (Appendix: BMI and Body Composition Measurements)
2. Consider monitoring other measures of adiposity, such as waist circumference.<sup>38</sup> (Appendix: BMI and Body Composition Measurements)
3. Conduct annual assessment of blood pressure/percentiles to monitor for pre-hypertension and hypertension. (clinical consensus)
4. Highlight dietary needs specific to living with Spina Bifida.
  - Discuss the importance of consuming fiber and water to manage bowel and bladder health. Sources of fiber include fruit, vegetables, whole wheat or whole grain bread and cereals. A mix of each along with regular fluids will help avoid constipation.<sup>5</sup>
  - Advise limiting sugary drinks such as juice, chocolate milk, and sports beverages.<sup>40-41</sup>
  - Discuss that children with Chiari malformation may have a sensitivity to different food textures.<sup>3</sup>

- Recommend that the child have access to food purchasing and preparation spaces. (clinical consensus)
  - Recommend a diet with adequate calcium and vitamin D for children with Spina Bifida, in order to avoid fractures due to osteoporosis.<sup>33</sup>
  - Consider that adults and families with lower incomes may experience food insecurity.<sup>1</sup>
  - Refer clients to National Center on Health, Physical Activity, and Disability (<http://www.nchpad.org>), which provides advice on nutrition and physical activity for persons with disabilities, including Spina Bifida.<sup>42</sup>
5. Provide families with nutritional information tailored to their circumstances.
- Take into account a family's geographical location, ethnicity, access to food, and other related factors when providing dietary education.<sup>43</sup>
  - Consider that adults and families with lower incomes may experience food insecurity.<sup>1</sup>
  - Encourage parents to include their children from an early age to participate in grocery shopping and food preparation, as appropriate to their age and ability.<sup>44</sup>
  - Suggest parents to let their children choose a new healthy food to try. Involving children in choices in food selection can lead them to increased independence and interest in their foods and to learn about making healthy choices. Repeating their exposure to healthy food options can increase children's acceptance and enjoyment of these foods.<sup>45</sup>
  - Involve children in discussions about healthy lifestyles in order to explore their understanding, perceptions, and priorities regarding nutrition.<sup>28</sup> If appropriate, ask parents to identify one or two small, healthy nutrition changes that they feel they could integrate into their daily life.<sup>46</sup>
  - Consider making a referral to a healthy lifestyle program and/or a smartphone application, while recognizing that few such programs are tailored to individuals with disabilities. (clinical consensus)
  - Celebrate any successes, such as drinking more water, introducing a new fruit or vegetable, cutting back on sugary drinks, and having regular meal times. Focus upon the strengths of the family.<sup>28</sup>
  - Highlight the importance of parents modeling healthy behaviors themselves to their children from an early age.<sup>23,30-31</sup> Encourage the whole family to get involved in healthy living activities not just the child with Spina Bifida.<sup>32</sup>
  - Understand that experiencing food insecurity may lead to a poor-quality diet, and have developmental consequences on the child.<sup>47</sup>
  - Highlight that children with Spina Bifida, especially those who are non-ambulatory, undertake low levels of physical activity, and have higher body fat levels or contractures, are at increased risk for bone fractures. Recommend a diet with adequate calcium and vitamin D.<sup>33</sup>
6. Screening for diabetes (fasting glucose, HbA1c or oral glucose tolerance test) is recommended every two years in children 10 years of age or older (or at the onset of puberty if it occurs at a younger age), and for all children with a Body Mass Index (BMI) over the ≥85th percentile and who have two or more additional risk factors including:<sup>36</sup>
- family history of type 2 diabetes mellitus (T2DM) in a first- or second-degree relative
  - high-risk ethnicity
  - acanthosis nigricans
  - hypertension
  - dyslipidemia

- polycystic ovary syndrome (PCOS)
7. Screening for dyslipidemia (fasting lipid profile) is recommended every two years for children up to 8 years of age with a Body Mass Index (BMI) over the 95th percentile or other risk factors for cardiovascular disease, such as:<sup>36</sup>
    - family history of dyslipidemia/early cardiovascular disease and/or morbidity in first- or second-degree relatives
    - history of diabetes, hypertension, or smoking in childhood
  8. Screening for dyslipidemia (fasting lipid profile) is recommended once for all children ages 9-11 years.<sup>36</sup>
  9. Provide guidance on maintaining good bowel health.
    - Explain that increased fiber in the child's diet will add bulk to the stool and make it easier to pass. Sources of fiber include fruit, vegetables, and wholemeal or whole grain bread and cereals.<sup>5</sup>
    - Recommend the same guidelines for daily fiber intake that are recommended for all children:<sup>34</sup>
      - 1-3 years: 19g
      - 4-8 years: 25g
      - 9-13 years: female–26g, male–31g
      - 14-18 years: female–26g, male–38g
    - Recommend that if the child is constipated, parents should increase fiber intake slowly over two to three weeks by adding one new high fiber food every two to three days. Increasing fiber too quickly can make the constipation worse or cause gas, cramping, and diarrhea. (clinical consensus)
    - Recommend more fluids, especially water and non-caloric fluids, which will also soften the stool and help with constipation. Follow the following 24-hour period daily maintenance fluid requirements calculation:<sup>35</sup>
      - 100 mL/kg for the first 10 kg body weight
      - + 50 mL/kg for the next 10 kg body weight
      - + 20 mL for every kilogram of body weight over 20 kg
    - Further guidance can be found in the Bowel Function and Care Guidelines.

## 13-17 years 11 months

### Clinical Questions

1. What is the most effective protocol to approach diet and nutrition goals in annual Spina Bifida clinic visits?
2. What are biggest barriers to healthy nutrition for children with Spina Bifida?
3. What self-management skills and resources related to healthy nutrition should be provided for children with Spina Bifida?
4. What is the best way to manage constipation with diet?
5. Are children with Spina Bifida and obesity at higher risk for metabolic syndrome?
6. Should screening for metabolic complications of obesity be performed?
7. Is there evidence to support the role of weight management intervention in the prevention of metabolic syndrome?

### Guidelines

1. Conduct annual assessments of weight, height or arm span, and BMI. (clinical consensus) (Appendix: BMI and Body Composition Measurements)
2. Consider monitoring other measures of adiposity, such as waist circumference.<sup>38</sup> (Appendix: BMI and Body Composition Measurements)
3. Conduct annual assessment of blood pressure/percentiles to monitor for pre-hypertension and hypertension. (clinical consensus)

4. Provide opportunities for teens and parents to talk about their priorities and concerns regarding nutrition and weight.
  - Discuss how nutrition can play an important role in helping individuals with Spina Bifida maintain a healthy weight; minimize skin breakdown, and increase activity and endurance.<sup>7</sup>
  - Discuss that children with Spina Bifida, especially those who are non-ambulatory, who undertake low levels of physical activity, and who have higher body fat levels or contractures, are at increased risk for bone fractures. Recommend a diet with adequate calcium and vitamin D.<sup>33</sup>
  - Provide regular opportunities for teens to discuss any concerns with their weight, growth and diet.<sup>27</sup> A trusting therapeutic relationship can greatly facilitate an honest and open discussion.<sup>28</sup>
  - Identify the teen's priorities and negotiate goals that meet those priorities as well as the parent's and clinician's goals.<sup>48</sup>
  - Use a strengths-based approach that highlights their nutritional achievements and celebrates successes.<sup>28</sup>
  - Discuss with parents, if relevant, that the Body Mass Index (BMI) is an imperfect indicator of health in all young people and especially in children with Spina Bifida due to difficulties measuring height and body composition.<sup>29</sup> Instead, show the child and parents the trajectory of the child's weight and height (or other measures of growth and adiposity) on a growth chart as a visual aid. Do not refer to growth cut-offs developed for typically developing children.<sup>1</sup> A steeply increasing trajectory would indicate that overweight or obesity may be a concern and warrant preventative strategies.<sup>28</sup>
  - Avoid using scare tactics in older children with Spina Bifida. Instead, discuss the following potential negative consequences of gaining excessive weight, as it relates to their individual circumstances:
    - Moving and transferring may become more difficult, which may also reduce independence and self-care activities.<sup>7</sup>
    - Increased pressure on the skin when seated for long periods of time (such as when using a wheelchair) may result in skin breakdown.<sup>49</sup>
    - Weight gain alongside existing scoliosis or kyphosis may result in additional breathing problems.<sup>5</sup>
  - Refer clients to National Center on Health, Physical Activity, and Disability (<http://www.nchpad.org>), which provides advice on nutrition and physical activity for persons with disabilities, including Spina Bifida.<sup>42</sup>
  - Consider referral to a "Healthy Lifestyle" program and/or use a mobile application, while recognizing that few such programs are tailored to individuals with disabilities (clinical consensus).
5. Consider the broader literature for all older children, given that there is little evidence that specifically refers teens with Spina Bifida. For instance:
  - Understand that eating habits generally worsen as children move into the teen years and become more autonomous.<sup>50</sup>
  - Emphasize the positive health benefits of breakfast and eating fruits and vegetables.<sup>31,51</sup> Skipping breakfast and low fruit and vegetable consumption is common in teens.<sup>52</sup>
  - Consider that food insecurity and lower socioeconomic status can be related to poorer diets.<sup>53</sup>
  - Emphasize that the family setting remains important for teens. Parental modelling, dietary intake, and encouragement are all associated with fruit and

vegetable consumption among teens.<sup>31</sup>

6. Discuss opportunities for the older child to participate in nutrition-related activities, such as:
  - Identify the teen's knowledge level about healthy eating habits. (clinical consensus)
  - Encourage the family to identify roles that the older child can play as part of daily life, such as in meal planning, shopping, and food preparation.<sup>54</sup>
  - Encourage older children to select a new healthy food to try, which can encourage broader food preferences.<sup>55</sup>
  - Identify the older child's existing strengths and resources regarding nutrition and how they can be built upon to reach their goals.<sup>56</sup>
7. Screening for diabetes (fasting glucose, HbA1c or oral glucose tolerance test) every two years with a Body Mass Index (BMI) over the ≥85<sup>th</sup> percentile and have two or more additional risk factors including:<sup>36</sup>
  - family history of type 2 diabetes mellitus (T2DM) in a first- or second-degree relative
  - high-risk ethnicity
  - acanthosis nigricans
  - hypertension
  - dyslipidemia
  - polycystic ovary syndrome (PCOS)
8. Screening for dyslipidemia (fasting lipid profile) is recommended every two years for children with a Body Mass Index (BMI) in the ≥85<sup>th</sup> percentile or other risk factors for cardiovascular disease (family history of dyslipidemia/early cardiovascular disease and/or morbidity in first- or second-degree relatives, history of diabetes, hypertension, or smoking in childhood.)<sup>36</sup>
9. Provide guidance on maintaining good bowel health.
  - Explain that increased fiber in the child's diet will add bulk to the stool and make it easier to pass. Sources of fiber include fruit, vegetables, and wholemeal or whole grain bread and cereals.<sup>5</sup>
  - Recommend the same guidelines for daily fiber intake that are recommended for all children:<sup>34</sup>
    - 1-3 years: 19g
    - 4-8 years: 25g
    - 9-13 years: female–26g, male–31g
    - 14-18 years: female–26g, male–38g
  - Recommend that if the child is constipated, parents should increase fiber intake slowly over two to three weeks by adding one new high fiber food every two to three days. Increasing fiber too quickly can make the constipation worse or cause gas, cramping, and diarrhea. (clinical consensus)
  - Recommend more fluids, especially water and non-caloric fluids, which will also soften the stool and help with constipation. Follow the following daily maintenance fluid requirements (24-hour period) calculation:<sup>35</sup>
    - 100 mL/kg for the first 10 kg body weight
    - + 50 mL/kg for the next 10 kg body weight
    - + 20 mL for every kilogram of body weight over 20 kg
  - Further guidance can be found in the Bowel Function and Care Guidelines.

## 18+ years

## Clinical Questions

1. How do nutrition issues vary by different demographics (e.g., age, geography, level of lesion, economic status, race and ethnicity, gender, and other characteristics) among adults with Spina Bifida?
2. What considerations should be given to nutritional intake when adults with Spina Bifida are taking medications to address other health concerns?
3. What is the best way to manage constipation with diet?
4. Are adults with Spina Bifida who have obesity at higher risk for metabolic syndrome?
5. Should screening for metabolic complications of obesity be performed in adults with Spina Bifida?
6. Is there evidence to support the role of weight management intervention in the prevention of metabolic syndrome?

## Guidelines

1. Conduct annual assessments of weight, height or arm span, and calculate BMI. (clinical consensus) (Appendix: BMI and Body Composition Measurements)
2. However, explain that BMI is not accurate for people with paralysis, who have lowered ratios of fat to lean muscle tissue and that looking at the trajectory over time may be more useful.<sup>57</sup>
3. Consider monitoring other measures of adiposity, such as waist circumference.<sup>38</sup> (Appendix: BMI and Body Composition Measurements)
4. Conduct an annual assessment of blood pressure or blood pressure percentiles to monitor for pre-hypertension and hypertension. (clinical consensus)
5. Tailor the discussion around healthy nutrition to the adult's context. Consider that adults and families with lower incomes may experience food insecurity.<sup>1</sup>
  - Refer clients to National Center on Health, Physical Activity, and Disability (<http://www.nchpad.org>), which provides advice on nutrition and physical activity for persons with disabilities, including Spina Bifida.<sup>42</sup>
  - Identify who requires the information about healthy food (i.e. the adult with Spina Bifida, the caregiver, the attendant, the family member, or others).<sup>1</sup>
  - Discuss the adult's existing access to cooking options and food preparation areas. (clinical consensus)
  - Involve a social worker or disability organization representative who can speak to adults about available local, state, and federal nutritional benefits such as the Supplemental Nutrition Assistance Program (SNAP), farmer's market vouchers or coupons, and other sorts of food vouchers that are available for eligible individuals.<sup>58-59</sup>
  - Consider referral to a "Healthy Lifestyle" program and/or use a smartphone application, while recognizing that few such programs are tailored to individuals with disabilities (clinical consensus).
6. Provide information about potential interactions between nutrition in foods and medications.
  - Highlight that some medications, such as corticosteroids, have side-effects including weight gain, increased appetite, high blood pressure and a higher risk of developing osteoporosis or diabetes.<sup>60</sup>
  - Provide information about specific foods and beverages that may interact with medications, such as antihypertensive, anticoagulant, or corticosteroid medications.<sup>61</sup>
  - Encourage adults to disclose any prescribed, over-the-counter or complementary and alternative medications they are taking to all of their health care professionals, including pharmacists. (clinical consensus)

- Emphasize the importance of reading medication labels to identify any dietary contraindications.<sup>1</sup> If this is difficult, discuss other ways that the adults could find out about potential contraindications, such as making the medication labels available in a larger font or asking the pharmacists for assistance.<sup>62</sup>
7. Screening for abnormal blood glucose is indicated as part of assessing cardiovascular risk assessment in adults aged 40 to 70 years who have a BMI > 25 kg/m<sup>2</sup>. Persons who have a family history of diabetes, have a history of gestational diabetes or polycystic ovarian syndrome, or are members of high risk racial/ethnic groups may be at increased risk for diabetes at a younger age or at a lower body mass index. Clinicians should consider screening earlier in persons with one or more of these characteristics.<sup>63</sup>
  8. Screening for dyslipidemia (fasting plasma profile) is recommended for men ≥ 40 years of age, and women ≥ 50 years of age or postmenopausal. Adults with the following risk factors should be screened at any age: current cigarette smoking, diabetes, arterial hypertension, family history of premature coronary heart disease, family history of hyperlipidemia, high risk ethnicity (individuals of First Nations or of South Asian ancestry), or the presence of rheumatoid arthritis, systemic lupus erythematosus, psoriatic arthritis, ankylosing spondylitis, inflammatory bowel disease, chronic obstructive pulmonary disease, chronic HIV infection, chronic kidney disease, abdominal aneurysm, or erectile dysfunction.<sup>64</sup>

## Research Gaps

1. Evidence-based guidelines for weight-management, obesity prevention, and obesity treatment specific to children and adults with Spina Bifida.
2. Accurate assessment of body composition in a standardized and accessible manner.
3. Growth curves and weight classification cut-offs specifically for children and adults with Spina Bifida.
4. Evidence about the energy needs of people with Spina Bifida across the lifespan that is based on their mobility methods.
5. Whether children and adults with Spina Bifida are at higher risk for metabolic syndrome.
6. Whether screening for metabolic complications of obesity should routinely be performed in children and adolescents with Spina Bifida.
7. Evidence for the role of weight management interventions in the prevention of metabolic syndrome.

## Appendix: BMI and Body Composition Measurements

Detailed instructions on anthropometric procedures can be found in the National Health and Nutrition Examination Survey (NHANES) Anthropometry Procedures Manual, located on the Centers for Disease Control and Prevention website [INSERT LINK: [https://www.cdc.gov/nchs/data/nhanes/2017-2018/manuals/2017\\_Anthropometry\\_Procedures\\_Manual.pdf](https://www.cdc.gov/nchs/data/nhanes/2017-2018/manuals/2017_Anthropometry_Procedures_Manual.pdf)]. The following are selected excerpts from the manual.

**Weight:** Weigh clients with light indoor clothing but without shoes, socks, and/or slippers using a digital chair or wheelchair scale. Ask the person to remove any heavy or excess clothing, braces, or other heavy items. If using a wheelchair scale, ask the person to remove any heavy items from the wheelchair.

**Height:** Measure to the closest millimeter with a portable stadiometer or length-measuring board. For infants, use an infantometer with a fixed head piece and horizontal backboard, and an adjustable foot piece.

***Children under four years of age:***

1. Ask the parent or guardian to remove the child's clothes except for diapers or underpants.
2. Ask an assistant to support the child's head while you position the feet. Ensure that the head lies in the Frankfort horizontal plane.
3. Apply gentle traction to bring the top of the head in contact with the fixed head piece.
4. Secure the child's head in the proper alignment by lightly cupping the palms of your hands over the ears.
5. Align the child's legs by placing one hand gently but with mild pressure over the knees.
6. With the other hand, slide the foot piece to rest firmly at the child's heels. The toes must point directly upward with both soles of the feet flexed perpendicular against the acrylic foot piece. To encourage the child to flex the feet, run the tip of your finger down the inside of the foot.

***If a person can stand unaided:***

1. Assist person to stand with his/her back against a wall mounted height scale (stadiometer) with heels together and eyes looking straight ahead (Frankfort plane).
2. Adjust the horizontal arm of the scale until it sits on top of the person's head.
3. The person's height is indicated by the position of the scale arm.
4. Record measurement in centimeters.

***If a person cannot stand, measure the person's length (recumbent):***

1. Ask the person to lie on a measuring board, face or front upward.
2. Position the person so feet are touching the footboard together, shoulders are relaxed and touching baseboard, arms at sides, legs straight and knees together, and crown of head is touching headboard.

***Where a measuring board is not available and/or for people with severe contractures, measure segmental length:***

1. Ask the person to lie on the measuring board (or examination table), face or front upward.
2. Measure from head to neck (just above shoulder).
3. Measure from shoulder to hip.
4. Measure from hip to knee.
5. Measure from knee to ankle bone.
6. And measure from ankle bone to bottom of foot.
7. Add measurements together and record in centimeters.
8. For people with scoliosis, measure both sides of the body.

**Other methods to assess height:**

Where height/length is challenging to assess, alternative methods have been shown to be useful, including arm span<sup>39</sup> and ulna length.<sup>65</sup>

**Arm span**

1. Extend both arms outward (each arm abducted to 90 degrees).
2. Measure from fingertip to fingertip using a metal rod across the area of the Adam's apple.
3. Record measurement in centimeters.
4. To calculate BMI using arm span length, multiply by 0.95 for those with mid-lumbar lesions (i.e. those who lack gluteus medius and maximus function and/or those who lack

foot dorsiflexion) and 0.90 for those with high lumbar/thoracic functional motor levels (i.e. those who lack quadriceps function).<sup>7</sup> Note that this refers to the functional level of lesion, not the anatomic level.

### **Ulna length measurement (Segmometer)**

1. First, determine which forearm to measure. Measure the forearm that has been least affected by trauma, injury, or progression of weakness when compared to the opposite side. Measure the non-dominant arm if both arms are not affected.
2. Support and position the arm in pronation with 90–110 degrees of elbow flexion.
3. Palpate the distal tip of the ulnar styloid process (the prominent bone of the wrist) and mark lightly with a pen. Make sure to palpate superiorly on the wrist to avoid mistaking the tendon of the extensor carpi ulnaris for the distal tip of the ulna.
4. Palpate the tip of the olecranon (the tip point of the elbow) and place one arm of the segmometer on the olecranon.
5. Place the other end of the segmometer at the tip of the ulnar styloid.
6. Measure in centimeters, to the nearest millimeter (e.g. 19.7 cm) to obtain ulnar length in centimeters.
7. Complete the following calculation for height:<sup>65</sup>
  - Male: height (cm) = (4.605 x ulnar length in cm) + (1.308 x age in years) + 28.003
  - Female: height (cm) = (4.605 x ulnar length in cm) + (1.315 x age in years) + 31.485

### **Body Mass Index (BMI):**

BMI should be calculated using both height and length as kilograms per meter squared (kg/m<sup>2</sup>) and classified using Centers for Disease Control and Prevention cut-offs (85th–95th percentile=overweight, above 95th percentile=obese).<sup>66</sup>

### **Occipital head circumference** (up to two years of age)<sup>13</sup>

1. Ask the parent/caregiver to hold the baby over their shoulder or sit with the baby in their lap.
2. Place the head circumference tape around the child's head so that the tape lies across the frontal bones of the skull; slightly above the eyebrows; perpendicular to the long axis of the face; above the ears; and over the occipital prominence at the back of the head.
3. Move the tape up and down over the back of the head to locate the maximal circumference. Tighten the insertion tape so that it fits snugly around the head and compresses the hair and underlying soft tissues.
4. Measure the circumference to the nearest 0.1 cm.

### **Waist circumference:**

1. Ask the patient to place him/herself in the following manner:
  - Clear the abdominal region.
  - Feet shoulder-width apart.
  - Arms crossed over the chest.
2. It is suggested to kneel down to the right of the patient in order to measure waist girth.
  - Palpate the patient's hips to locate the top of the iliac crest.
  - Draw a horizontal line halfway between the patient's back and abdomen.
3. Place the measuring tape horizontally around the patient's abdomen (\*to work comfortably, it is suggested to wrap the tape around the patient's legs and then move up).
4. Align the bottom edge of the tape with your marked point.

5. It is recommended to use a measuring tape with a spring handle, such as the Gulick measuring tape, in order to control the pressure exerted on the patient's abdomen.
  - Gently tighten the tape around the patient's abdomen without depressing the skin.
6. It is suggested to request the patient to relax and breathe NORMALLY (abdominal muscles should not be contracted).
  - Ask the patient to take two or three NORMAL breaths.
  - Measure from the zero line of the tape to the nearest millimeter) at the end of a NORMAL expiration.
7. Note the lesion level and/or any bulky masses, liposuction incision marks or spinal curvature.

### **Waist circumference in supine**

1. Ask the patient to lie down and place him/herself in the following manner:
  - Clear the abdominal region.
  - Arms crossed over the chest.
2. Palpate the patient's hips to locate the top of the iliac crest. If iliac crest cannot be located, measure smallest part of abdomen.
  - Draw a horizontal line halfway between the patient's back and abdomen.
3. Complete steps 3-6 as indicated above.

### **Skinfold thickness**

1. Ask the patient to remove their shirt if comfortable and clear the abdominal region.
2. Begin with right arm placed at a 90-degree angle and request that the patient places his/her arm across the abdomen, with the palm facing inward.

#### **Triceps:**

- Along the midline on the back of the triceps of the right arm, determine the midpoint located between the top of the acromial process (top of shoulder) to the bottom of the olecranon process of the ulna (elbow).
- Pinch the skin to create a vertical skinfold with the thumb and forefinger about 0.5 inches from the measurement site.
- Release the calipers on the skinfold three times for 1 second each and record the measurements.

#### **Subscapular:**

- Ask patient to place arm behind his/her back
- The skinfold should angle 45 degrees from horizontal, in the same direction as the inner border of the scapula
- Release the calipers on the skinfold three times for 1 second each and record the measurements
- Use the Slaughter equation to calculate the estimated body fat.<sup>67</sup>

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