

# Guidelines for the Care of People with Spina Bifida

## 3-5 years 11 months

### **Care Coordination Guidelines**

1. It is recommended that the Spina Bifida Care Coordinator provide developmentally-appropriate care education across the spectrum of symptoms and conditions related to Spina Bifida to empower families and children to manage their own care and be able to recognize when complications and emergencies arise. The coordinator should also identify and/or improve gaps in the family knowledge base specifically related to the preschool period (mobility progress, skin inspection, bowel and bladder care, speech/cognitive development, and more). (clinical consensus) (Bowel Function and Care Guidelines, Mental Health Guidelines, Mobility Guidelines, Neuropsychology Guidelines, Skin (Integument) Guidelines, Urology Guidelines)
2. It is recommended that the Spina Bifida Care Coordinator prepare the family for early independence, entering preschool, and planning special education and health-related services in the school. (clinical consensus)
3. It is recommended that the Spina Bifida Care Coordinator coordinate with the family and multidisciplinary Spina Bifida care team to ensure that the child with Spina Bifida is up-to-date on all sub-specialty care visits including, imaging, monitoring, and equipment needs, where appropriate, including assistance with insurance authorization when needed.
4. It is recommended that the Spina Bifida Care Coordinator assess family dynamics in coping with the diagnosis and evaluate psychosocial stressors for the family. The Spina Bifida Care Coordinator should also assist with referrals to mental health and social services when appropriate. (clinical consensus) (Mental Health Guidelines) . When applicable, it is recommended that the Spina Bifida Care Coordinator update the primary care provider on the current care goals and recommendations of the Spina Bifida multidisciplinary care team. Use two-way communications to identify and address medical concerns and obtain updated records from the person's primary care provider such as immunizations, growth charts, developmental screenings, and other materials.
5. It is recommended that the Spina Bifida Care Coordinator serve the family as the lead contact person and information-provider for the multidisciplinary medical services for the child with Spina Bifida. The Spina Bifida Care Coordinator should monitor the family's needs and prescriptions for durable medical equipment, supplies, and medications, as needed.

### **Health Promotion and Preventive Health Care Services Guidelines**

1. Inform families about the importance of routine pediatric care, developmental surveillance and anticipatory guidance (e.g., immunizations and vision and hearing screens).
2. Promote age-typical health promotion counseling (e.g., counseling for car seats or other motor vehicle occupant restraints, water safety, and skill development). Counseling should be individualized to accommodate for Spina Bifida comorbidities such as having a shunt, mobility

impairments, orthopedic deformities, developmental delays, and bowel and bladder management. (Bowel Function and Care Guidelines, Mobility Guidelines, Neuropsychology Guidelines, Neurosurgery Guidelines, Orthopedics Guidelines, Urology Guidelines)

3. Counsel families about possible future medical and social needs related to living with Spina Bifida. Needs might include latex allergies, chronic urinary issues, problems with shunts, achieving an inclusive environment, overweight/obesity risk,<sup>9</sup> importance of physical and recreational activity, managing unexpected changes in function, keeping regular medical appointments, and pain. (Bowel Function and Care Guidelines, Latex Guidelines, Nutrition, Metabolic Syndrome, and Obesity Guidelines, Physical Activity Guidelines, Urology Guidelines)

4. Monitor the child for neglect and abuse. (Family Functioning Guidelines)

### **Transition Guidelines**

1. Provide updates for families regarding a probable trajectory for adult function and expectations for optimal independence according to the child's abilities and chronic condition status.

2. Provide updates for families on information regarding long-term financial, insurance, and supportive living planning based on the child's probable trajectory into adult function.

3. Review expectations as to where individuals with Spina Bifida can access comprehensive care throughout the lifespan including chronic condition management, preventative care, and transition care.

### **Family Functioning Guidelines**

1. Provide support and ongoing counseling as needed to parents, the child, and siblings.

2. Provide anticipatory guidance for parents regarding possible behavioral challenges and autonomy needs in children with Spina Bifida and their siblings. (Mental Health Guidelines, Neuropsychology Guidelines)

3. Teach parents to advocate for themselves and their child when working with medical, educational, and agency staff. (clinical consensus)

4. Be aware that although interventions should target all families, some families are particularly at-risk for adjustment and adherence difficulties (e.g., those from lower socioeconomic backgrounds and single-parent families).

5. Re-assess parenting skills such as discipline, behavior management, and sibling relationships.

6. In the context of family functioning, address self-care abilities and refer to therapies (OT, PT). (clinical consensus)

7. Discuss issues that affect children with Spina Bifida when they transition to school. (clinical consensus)

8. Advise parents of their child's right to free and appropriate education in the least restrictive environment through the public schools (i.e., explain services available under the Individuals with Disabilities Education Act). (clinical consensus)

9. Assess the family context for helping the child to develop self-management skills and to carry out medical regimens and identify possible barriers to adherence. (Self-Management and Independence Guidelines, Transition Guidelines)

### **Mental Health Guidelines**

1. Discuss with parents the importance of their child's socialization and developing friendships with their peers and taking advantage of opportunities for activities. (Family Functioning Guidelines, Neuropsychology Guidelines)
2. Encourage participation in preschool educational programs. (clinical consensus)
3. Discuss the importance of making and keeping schedules/routines, doing chores, modeling behaviors, and making age-appropriate choices and decisions. (clinical consensus)
4. Assess social and psychological development and identify resources that build on strengths and encourage resilience.
5. Refer for social skills training as indicated.
6. Include optimization of mental health when developing an Individualized Education Program (IEP, IFSP or 504 Plan). (clinical consensus) (Appendix: Early Intervention Services, Individualized Educational Plans (IEP) and 504 Plans)
7. Provide additional age-appropriate information about Spina Bifida as the child grows.
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. (clinical consensus) ) (Appendix: Early Intervention Services, Individualized Educational Plans (IEP) and 504 Plans)

### **Quality of Life Guidelines**

1. Assist families in their efforts to facilitate the development of protective psychosocial behaviors (e.g. showing affection, bouncing back when things don't go the child's way, showing interest in learning new things). Encourage independence, praise for accomplishment, and provide opportunities for fun. (clinical consensus) (Family Functioning Guidelines, Mental Health Guidelines)
2. Address assessment of executive function. (clinical consensus) (Neuropsychology Guidelines)
3. Target strategies to optimize the child's bowel program because bowel incontinence is consistently related to HRQOL. (clinical consensus) (Bowel Function and Care Guidelines)

### **Self Management and Independence Guidelines**

1. Provide instruction and support to families regarding knowledge, skills, and behaviors needed to manage their child's Spina Bifida and related issues. (clinical consensus)
2. Discuss the need to expand the range of daily life activities and chores, as well as strategies to accommodate the child's learning style and/or mobility.
3. Provide anticipatory guidance that autonomy skills are maximized when positive behaviors are reinforced and clear and consistent consequences for inappropriate behavior are used. (clinical consensus) (Mental Health Guidelines, Neuropsychology Guidelines)
4. Refer to community resources such as early education programs that promote autonomy, self-efficacy, and other foundational independence skills. (clinical consensus) (Appendix: Early Intervention Services, Individualized Educational Plans (IEP) and 504 Plans)

## **Neuropsychology Guidelines**

1. It is essential to carefully monitor the development of attention and self-regulation skills; these begin to emerge as a separate domain and directly affect the subsequent development of cognitive, academic, and social skills. Expectations for independent problem solving, responsibility, and social interactions are critical for school performance and psychosocial adjustment. Preschoolers with SBM show early manifestations of attention, pragmatic language, and math difficulties that subsequently emerge as major factors in academic and social adjustment. Patients with identified concerns, even if mild, require timely referrals to the local special education preschool program and/or outpatient providers (e.g., psychologist, developmental pediatrician). (clinical consensus)
2. Monitor language comprehension problems because interventions may facilitate the development of vocabulary and conversational speech that are essential for reading comprehension later in school.
3. Carefully observe children with more severe hydrocephalus, hypogenesis and/or severe hypoplasia of the corpus callosum and history of central nervous system infection because they are at greater risk for difficulties involving construction of meaning from language. These skills need to be carefully tracked by preschool education teams or through formal assessments with neuropsychologists, developmental specialists, or speech and language pathologists. (clinical consensus)
4. As part of the child's medical team, advocate for children to have access to high quality public education with related services that support the development of attention, self-regulation, social interaction skills, and independence. If parents choose private school or decide to homeschool, then formal assessments and recommendations for support services and supplemental resources should be provided in those settings as well. All children, regardless of placement, can and should be evaluated for eligibility for special educational services when learning problems are present. (clinical consensus)
5. Although it should not matter as to which of the 13 categories of special education a child is identified, "other health impaired" (or neurological disorder classifications in some states) helps schools understand that potential learning difficulties are related to the underlying neurological disorder. Help all individuals who interact with the child understand that SBM is not simply an orthopedic condition or "physical disability." Brain malformations and hydrocephalus (with or without shunting) affect learning, especially in areas that require the construction and integration of information such as language, reading comprehension, and mathematics.
6. Monitor development with assessments of early math and literacy skills to help establish more subtle difficulties with development and the need for more tailored educational supports. 7. When available, consider full neuropsychological evaluations that include the assessment of early literacy and numeracy skills. Neuropsychological assessments provide a more comprehensive understanding of strength and weakness, as well as significant discrepancies that may not be captured by psycho-educational testing that is provided by school districts. (clinical consensus)

## **Neurosurgery Guidelines**

### **Patient/Family**

1. Teach the family to learn about and observe the child for clinical signs of shunt failure, brainstem dysfunction, TSC and syringomyelia. (clinical consensus)
2. Foster and develop working relationship with the team of Spina Bifida providers.1,15 (clinical consensus)

#### **Providers/neurosurgeons/Spina Bifida clinic**

1. Follow children aged 3-5 years 11 months at intervals of 6-12 months in the Spina Bifida clinic. (clinical consensus)
2. Teach families about and review the signs of acute shunt failure (headache, vomiting, and lethargy/sleepiness), and chronic shunt failure (low grade recurring headache and neck pain, loss of developmental milestones). Follow the child clinically to observe for these signs. (clinical consensus)
3. Teach families the signs of brain stem dysfunction that might occur in this age range (poor control of oral secretions, swallowing dysfunction, stridor, and impaired language acquisition). Follow the child clinically observing for these signs. (clinical consensus)
4. Teach families the signs of TSC (back pain, declining lower extremity sensorimotor function) and urologic dysfunction. Follow the child clinically to observe for these signs.
5. Teach families of signs of syringomyelia (back pain, sensory changes in hands). Follow the child clinically to observe for these signs. (clinical consensus)
6. Use adjunctive studies judiciously (imaging such as MRI/CT, urodynamics, and sleep and swallow studies) during routine visits with the well child, according to experience, preference and best clinical judgment, to augment clinical decision-making. (clinical consensus)

#### **Mobility Guidelines**

1. Assess neurologic level and strength changes using standardized assessment tools at each clinic visit. Monitor for changes in gait, sensation, bowel and bladder function, and musculoskeletal changes. (clinical consensus)
2. If the child is not pulling to stand, consider using a standing frame or mobility device to get him or her upright and weight bearing. (clinical consensus)
3. Emphasize mobility options for all children including ambulation and wheelchairs. Make sure parents are aware that all children who have the potential to walk may have some delay in achieving this milestone.
4. Use appropriate bracing to assist weak muscles and protect the lower limbs from torque and shear forces.
5. Ensure proper wheelchair fit, posture, and technique in children who use wheelchairs, in order to reduce energy expenditure and promote long-term function. (clinical consensus)
6. Have an understanding of the coverage for durable medical equipment (DME) and how this relates to current and future DME needs. (clinical consensus)
7. Encourage weight-bearing activities every day to promote bone health. (clinical consensus)
8. Collaborate with orthopedic specialists to monitor for age specific musculoskeletal problems. (Orthopedic Guidelines)

#### **Orthopedics Guidelines**

1. Evaluate gait with careful attention to orthopedic deformities that render gait inefficient and preclude orthotic management. (clinical consensus)
2. Consider derotational osteotomy when rotational abnormality adversely impacts ambulation.
3. Consider treating foot deformities with stretching, casting, bracing, soft tissue release or tendon transfers to facilitate orthotic management. (clinical consensus)
4. Evaluate the spine clinically and obtain scoliosis radiographs every one to two years if a progressive spinal deformity is suspected. Perform radiographs in a sitting position in children who can sit but not stand and in a standing position in children who can stand. (clinical consensus)
5. Work with neurosurgery specialists to determine whether a neurogenic cause of scoliosis progression is present. (clinical consensus) (Neurosurgery Guidelines)
6. Consider bracing for progressive, non-congenital scoliosis in the 25 to 50-degree range. (clinical consensus)
7. It is recommended that surgical treatment of scoliosis be reserved for a progressive deformity that is unresponsive to non-operative management. For example, when there is progression of the scoliosis in spite of bracing and after a neurosurgical cause, such as a tethered cord, has been ruled out. It is also recommended that management with growing rod surgery and fusionless technique should include spinal cord monitoring in patients with distal neurologic function.
8. Consider surgical treatment of gibbus deformity for intractable skin breakdown or to free up the upper limbs for independent sitting.
9. Teach children and families about fractures and related deformities. (clinical consensus)

### **Physical Activity Guidelines**

1. Discuss with parents and caregivers the importance of involving the child in recreation, physical activity, limiting sedentary behaviors and engaging in social programs/services where they can be actively engaged with peers who have and those who don't have a disability. Also, give parents/caregivers information about the life-long benefits of physical activity (e.g. active adults with Spina Bifida report more functional independence and a higher quality of life compared to those with Spina Bifida who are inactive). (Health Promotion and Preventive Health Care Services Guidelines)
2. Discuss strategies with parents/caregivers that balance parental involvement in their child's physical activities and the child's need for autonomy to increase independence.
3. Identify and provide additional support and information on precautions that children with shunts and ambulatory limitations should take when being physically active.
4. Use a team approach and include PTs/OTs to work with parents/caregivers to ensure children have proper fitting mobility equipment to maximize participation in physical activity. (clinical consensus)
5. Educate parents/caregivers of their child's right to adapted physical education/activity in preschool and encourage parents/caregivers to advocate for physical activity goals

### **Sexual Health and Education Guidelines**

1. Provide factual information to parents and caregivers and encourage them to provide developmentally-appropriate sexual education to their children, including information about appropriate versus inappropriate touching.
2. Explore the parent's expectations regarding their child's sexual development.
3. Explain that sexual exploration is a normal and healthy part of early childhood development.
4. Underscore the goal of continence (Bowel Function and Care Guidelines, Urology Guidelines) for optimal sexual relationships in the future. (clinical consensus)
5. Review relevant literature that addresses sexual health and education, such as "Bright Futures" and other reports prepared by the American Academy of Pediatrics.
6. Provide education about pubertal development, evaluate concerns or abnormal physical findings, and explain the risks of precocious puberty. (Endocrine: Puberty and Precocious Puberty)

### **Urology Guidelines**

1. Obtain a renal/bladder ultrasound yearly, if the child is stable. (clinical consensus)
2. Obtain a renal/bladder ultrasound as needed, if the child has recurrent symptomatic UTIs or if urodynamic testing identifies bladder hostility. (clinical consensus)
3. Obtain urodynamic testing only if the following are present: (clinical consensus)
  - upper tract changes
  - recurring UTIs
  - interest in beginning a urinary continence program
4. If the child is on CIC, begin to involve the child in the process of self-catheterization. (clinical consensus) (Self-Management and Independence Guidelines)
5. Obtain a serum creatinine test if there is a change in imaging of the upper urinary tract. (clinical consensus)
6. Obtain serum chemistries (includes serum creatinine) at age 5. Assess suspected UTIs with a catheterized urine specimen. Repeat a positive bag urine specimen with a catheterized specimen. (clinical consensus) Define a UTI by:
  - a positive UA, and
  - a positive urine culture (UC) on a catheterized specimen, and
  - leakage between CIC, and
  - onset of pelvic or back pain, and
  - fever (100.4 F / 38.0 C).

Define a positive UA (+ UA) as:

- >trace nitrite or leukocyte esterase on dip UA, and
- >10 white blood cells/high power field (WBCs/hpf), uncentrifuged specimen, or
- >5 WBCs/hpf, centrifuged specimen.

Define a positive UC (+UC) as:

- >50,000 colony forming units/milliliter (CFUs/mL) (sterile specimen obtained by catheter or suprapubic aspirate).

- >100,000 CFUs/mL in a clean voided specimen.
7. Initiate CIC and antimuscarinic therapy when indicated by upper urinary tract changes, recurring symptomatic UTIs, or bladder hostility noted on urodynamic testing. (clinical consensus)
  8. Introduce urinary continence and discuss interest in beginning the program and options at each visit. (clinical consensus) (Self-Management and Independence Guidelines)
  9. Introduce bowel management and discuss interest and options at each visit. (clinical consensus) (Bowel Function and Care Guidelines)

### **Bowel Function and Care Guidelines**

1. Discuss consequences of constipation and bowel incontinence (including shunt malfunction, urinary tract infections (UTIs), skin breakdown, social isolation).
2. Establish the goal of bowel continence and institute the bowel continence program using guidelines below.
3. Focus on fiber, fluids, exercise, and timed bowel movements after meals.
4. Consider two-pronged approach of oral and rectal interventions to meet the goal of bowel continence without constipation or fecal incontinence.
5. Use dietary management (fiber and fluids), pharmacologic adjuncts (sennoside, polyethylene glycol), and/or rectal stimulants (glycerin, docusate sodium, or bisacodyl suppositories) to manage constipation and fecal incontinence.
6. Use barrier creams to protect perineal area from breakdown as needed.
7. Refer to a Spina Bifida clinic or specialist with expertise in bowel management in Spina Bifida. (clinical consensus)

### **Endocrine: Puberty and Precocious Puberty Guidelines**

1. Monitor and document weight and height velocity closely at every health supervision visit. Height should be measured (if possible) using a stadiometer. Often there may be difficulty assessing height due to inability to stand, scoliosis or contractures. In these cases, arm span or another appropriate parameter may be used. Care should be taken to use the same parameter at subsequent visits. (clinical consensus)
2. Perform a complete physical exam, including of the breasts and genitalia, at each health supervision visit. Offer for the exam to be completed by a provider of the same sex if the child and/or family is more comfortable with a same-sex provider. (clinical consensus)
3. Document all positive and negative findings of the physical exam. (clinical consensus)
4. Discuss the outcomes of the evaluation with the parents or caregivers and ask them if they have any concerns. (clinical consensus)
5. Refer the child to a pediatric endocrinologist if abnormal signs of puberty are observed. Abnormal signs could include progressive breast development over a 4- to 6-month period of observation or progressive penis and testicular enlargement, especially if accompanied by rapid linear growth. Children exhibiting these true indicators of early puberty need prompt evaluation by an appropriate pediatric endocrinologist.

## **Endocrine: Short Stature and the Effects of the Human Growth Hormone**

### **Guidelines**

1. Assess weight, height at each health supervision visit. If height is not able to be measured using a stadiometer, it is recommended that a consistent parameter (such as arm span) should be measured and recorded. (clinical consensus)
2. Have a discussion with the family about the expected height of the child, based on the limitations due to myelomeningocele and the parents' height. (clinical consensus)
3. Discuss the risks and benefits of hGH therapy with the parents. (clinical consensus)
4. If concerns about growth arise, a referral to a pediatric endocrinologist is recommended for growth assessment, IGF-1, IGF Binding Protein-3, and GH stimulation tests. (clinical consensus)
5. If hGH treatment is initiated, monitor pituitary function, scoliosis, tethering of spinal cord, growth velocity, and pubertal development. This may be done in collaboration with a pediatric endocrinologist. (clinical consensus)

### **Integument ( Skin) Guidelines**

1. Teach parents and caregivers to inspect the skin daily (especially weight bearing or insensate areas) for changes in color, texture, and temperature.
2. Encourage the child's involvement in skin inspection.
3. Teach child to develop awareness of insensate areas.
4. Review with parents and caregivers the consequences of heat, moisture, or pressure related to insensate areas.
5. Recommend the use of barrier creams to protect the skin from damage as a result of bowel and bladder incontinence.
6. Discuss the need to check water temperature and encourage the use of a bath water thermometer.
7. Tell parents and caregivers to check for hot surfaces that have been exposed to the sun such as car seats and playground equipment.
8. Teach parents/caregivers how to inspect for well-fitting orthoses.
9. Teach parents and caregivers that the child should wear protective clothing and footwear (including water shoes in a pool or on pool deck) over insensate areas.
10. Tell parents and caregivers to seek treatment if the child's skin is compromised.

### **Latex and Latex Allergy Guidelines**

1. Screen toys and the environment of preschoolers as they start to interact with their peer group more regularly. Keep children away from toys and other products that contain latex such as latex-containing urinary catheters. (clinical consensus) (Appendix 1)
2. Discuss avoidance of rubber balloons at parties, school activities, restaurants, and other gathering places for events.
3. Teach children to ask questions about items that may contain latex.
4. Teach children, at a very basic level, to avoid latex products.

5. Help children and parents identify latex-free substitute products, such as Mylar balloons, for celebrations. (clinical consensus) (Appendix 1)
6. Instruct families to check that food made in public venues has been prepared with latex-free gloves. (clinical consensus)
7. Refer to an allergist when the child is allergic to latex but does not know if he or she is allergic to cross-reacting foods; this is particularly crucial in those who have had a systemic or anaphylactic episode. (Appendix 2) If a positive test is found, then a food challenge would be indicated in the case where there is no history of food-related clinical reaction. Many of the positive tests may be due to laboratory cross-reactivity, but a clinical response of allergy will not be provoked.

### **Nutrition, Metabolic Syndrome and Obesity 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. A trusting therapeutic relationship can greatly facilitate an honest and open discussion.
  - 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.
  - Consider that adults and families with lower incomes may experience food insecurity.
  - Highlight that early eating patterns and relationships with food are critical for ongoing good nutrition through the lifespan.
  - 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).
  - 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. A steeply-increasing trajectory would indicate that overweight or obesity may be a concern and warrant proactive discussions of preventative strategies.
  - 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.
  - Consider monitoring other measures of adiposity, such as waist circumference. (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.
  - 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

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.

- Recommend the same guidelines for daily fiber intake that are recommended for all children:

- 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.

### **Sleep Related Breathing Disorders Guidelines**

1. Recognize that the symptoms of SRBD in children (mouth breathing, a history of delayed growth, features of inattention and hyperactivity) are different compared to adults (snoring and excessive daytime sleepiness are less frequent).

2. Ask questions related to sleep quality, quantity and other possible symptoms at every visit (at least annually). Standardized screening questionnaires for SRBD in children are useful in clinical settings.

3. Further evaluate changes in respiratory status/function.

4. Discuss sleep disordered breathing with parents and care providers so they can better observe for early symptoms or changes.