

Guidelines for the Care of People with Spina Bifida

0-11 Months

Care Coordination Guidelines

1. After the Spina Bifida diagnosis has been made, it is recommended that the Spina Bifida Care Coordinator should be readily available to the family to provide support 9 and education throughout the pregnancy. These consults may take place as part of a maternal fetal health visit in a high-risk pregnancy center. The goals of the consults may include to:

- assist the family with coping with the new diagnosis,
- provide overall education on what the family can expect ages 0-11 months and while in their stay in the neonatal intensive care unit (NICU) stay, and
- provide general information on the signs and symptoms related to Spina Bifida. The Spina Bifida Care Coordinator may assist in synchronizing prenatal visits for other subspecialties that could include neurosurgery, urology, and orthopedics. The primary role of the Spina Bifida Care Coordinator during this stressful time for families is to convey the message that the family is not alone because a well-prepared team will be on hand to provide them with the support they need to help care for their child. 10

2. It is recommended that the Spina Bifida Care Coordinator should use the time during pregnancy or 0-11 months to introduce the family to the Spina Bifida clinic and multidisciplinary team (when one is available) and begin the process of arranging post-discharge follow-up.

Through counseling and encouragement, the Spina Bifida Care Coordinator:

- assists the family to accept the diagnosis, and
- contacts the medical home of the family and infant with Spina Bifida and identifies the specific lead professional or nurse case manager who will serve as the point of contact for the family to provide education, resources, and support.10-11

3. It is recommended that the Spina Bifida Care Coordinator provide families with a broad and appropriate early education across the spectrum of symptoms and conditions related to Spina Bifida. This may include educating the family on early urologic work-up and management and possibly teaching them about clean intermittent catheterization (CIC). Other topics may include education on latex allergy and precautions, education regarding early orthopedic interventions, and education to help families recognize potential neurosurgical complications. (clinical consensus) (Latex and Latex Allergy in Spina Bifida Guidelines, Neurosurgery Guidelines, Orthopedics Guidelines, Urology Guidelines)

4. It is recommended that the Spina Bifida Care Coordinator work closely with the NICU staff to ensure that parents have the necessary skills and education for discharge and a smooth transition to home care. (clinical consensus)

5. It is recommended that the Spina Bifida Care Coordinator should communicate and collaborate between the family and the multidisciplinary and sub-specialty Spina Bifida team members to arrange and execute the child's follow-up appointments, monitoring, and care plan.2,12

6. When applicable, it is recommended that the Spina Bifida Care Coordinator should update the child's primary care provider and/or medical home 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 medical home, such as immunizations, growth charts, developmental screenings, and other materials.^{4,11}
7. When appropriate, it is recommended that the Spina Bifida Care Coordinator should refer families to early intervention services. (clinical consensus) (Appendix: Early Intervention Services, Individualized Educational Plans (IEP) and 504 Plans) ¹⁰
8. It is recommended that the Spina Bifida Care Coordinator make referrals to local Spina Bifida Association Chapters and parent support groups, as available. (clinical consensus)
9. It is recommended that the Spina Bifida Care Coordinator should monitor the parent's and caregiver's compliance with appointments, and problem-solve with them if non-compliance is noted. (clinical consensus)
10. When appropriate, it is recommended that the Spina Bifida Care Coordinator should assess family dynamics in how they are coping with the diagnosis, evaluate psychosocial stressors for the family, and assist them with referrals to mental health and social services professionals. (clinical consensus) (Mental Health Guidelines)

Health Promotion and Preventive Health Care Services

1. Inform families about the importance of routine pediatric care, developmental surveillance and anticipatory guidance (e.g., immunizations and vision and hearing screens).⁹⁻¹⁰
2. Provide age-typical health promotion counseling (e.g. counseling for car seats or other motor vehicle occupant restraints, water safety, and nutrition).⁹⁻¹⁰ 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.^{10,12} (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,^{5,13} chronic urinary issues,^{3,13} problems with shunts, and achieving an inclusive environment.^{2,13} (Latex Allergy Guidelines, Mobility Guidelines, Neurosurgery Guidelines, Urology Guidelines)
4. Monitor the child for neglect and/or abuse.⁹⁻¹⁰ (Family Functioning Guidelines)

Prenatal Counseling Guidelines

1. Convey information about the medical care and lifelong functional impact of Spina Bifida in a value-neutral, collaborative manner while seeking from families an understanding of their needs, values, and beliefs.

- Ideally, consultations with the parents will take place shortly after identification of the NTD is made at the 18th week and before the 24th week of gestation.
 - Efficient consultation is essential and should happen quickly, soon after the identification of the NTD, to allow parents the broadest array of options and to provide enough time to consider the option for fetal surgery. (clinical consensus)
 - Base consultation with families on a collaborative, shared decision-making model that includes the medical team and parents. (clinical consensus) • Avoid using words that assign value or bias, such as “risk,” “bad news,” and “bad outcomes.” Use words that impart the importance of the decision, such as “important news,” “significant outcome,” and “potential challenges.” This allows parents to assign their own values to the news provided.
 - Offer a review of prenatal testing and results to clarify any misunderstandings or confusion that may exist. Typically, the diagnosis is made by a high-resolution ultrasound examination that is performed during the second trimester at a maternal–fetal medicine unit. An ultrasound can define the location and size of the lesion, whether it is open or closed (in most instances), and secondary findings such as hydrocephalus. Given the increased risk of other abnormalities, fetal echocardiography should be considered. Genetic evaluation by amniocentesis for chromosomal microarray should be recommended because the identification of a genetic abnormality in a fetus with an NTD has important implications for counseling regarding prognosis, pregnancy management, and determining whether the patient is a candidate for in-utero NTD repair. Measurement of amniotic fluid acetylcholinesterase helps to differentiate between open and closed NTDs and is a component of many preoperative evaluations for fetal repair. Fetal MRI also may be considered for assessment of unclear findings on ultrasonography.
 - Expect to provide critical information about the likelihood of survival and the spectrum of outcomes (i.e. neurosurgical, cognitive, developmental, urologic, orthopedic, dermatologic) for children with NTDs.
 - Discuss disability. Provide information on outcomes with a lifespan approach.
 - Review general principles associated with lesion levels, as well as the difficulty with providing specific predictions based on lesion level.
 - Review treatment options for conditions associated with NTDs with an emphasis on functional outcomes.
2. Review evidence-based treatment options with the family, including fetal surgery.
- Treatment options should include prenatal closure for open NTDs offered at treatment centers with expertise in the surgical and obstetrical management of NTDs. It is recommended that fetal surgery and the details of the surgical and obstetrical impacts should be reviewed by surgeons/obstetricians with experience managing high-risk pregnancies and/or providing care to infants with NTDs.
 - In addition to the option for prenatal closure, also present the option for term delivery and postnatal closure for open NTDs. Explain to parents and caregivers that cesarean delivery at 37 weeks and closure within 24 hours of delivery is generally recommended when the decision is made for postnatal closure. Ensure that the parents are aware of what to expect at birth and after the surgery.

- Although closed NTDs usually do not require surgical intervention in the newborn period, it is recommended that they have the same monitoring and investigations in the newborn period as open NTDs. (clinical consensus)

- Present adoption as an option for parents who are not open to termination but are not able to raise a child with a disability. (clinical consensus)

- Review termination of the pregnancy as another option for the family.

3. Offer families the opportunity to meet with key members of the Spina Bifida care team:

- Specialists in fetal medicine and/or obstetrical medicine are familiar with managing pregnancies complicated by a prenatal diagnosis of NTD. These providers are first to share the results of the testing. The prenatal diagnosis of Spina Bifida should be made in a value-neutral manner.

- Neurosurgeons provide information about management approaches such as fetal surgery and postnatal closure. Neurosurgeons experienced with and dedicated to caring for patients with neural tube defects (NTDs) are uniquely qualified to discuss both short term and realistic long-term expectations and challenges facing a child born with Spina Bifida.

- Experts in clinical genetics can clarify test results, discuss the genetics of NTDs, provide information about folic acid, and discuss recurrence risk and potential impact on future pregnancies.

- Developmental pediatricians, advanced practice nurses, and physiatrists focus on childhood disabilities and how to optimize function. These specialists can provide essential insight into potential medical needs and functional goals across the lifespan. They provide parents with evidence-based, up-to-date information. They can also assist with resource identification, access to care, and utilization, including caregiver support and mental health resources.(Family Functioning Guidelines, Mental Health Guidelines)

- Social workers provide critical emotional support and screening for parental mental health and are recommended to be included in all consultations. They provide families with links to important financial resources and sources of emotional support, including caregiver support and mental health resources. They can also provide information to families about local, national, and international sources. (Family Functioning Guidelines, Mental Health Guidelines)

- Urologists and orthopedists can provide more detailed discussions on interventions available for optimizing functional outcomes.⁵ (Orthopedic Guidelines, Urology Guidelines)

- Neonatologists can provide information and resources in advance about the child's immediate care needs such as breastfeeding, skin-to-skin care, and tours of the neonatal intensive care unit (NICU).

4. Offer information about what to expect at birth.

- Review that the child may need to be admitted to a special care or intensive care nursery (all with open NTDs, some closed NTDs may be cared for collaboratively with the nursery and community teams) and that psychosocial support is available to them in that setting. (Family Functioning Guidelines, Mental Health Guidelines)

- Help families to anticipate that specialists in Spina Bifida will need to be present at the delivery to examine the child, that there exists the possibility that intravenous fluids/antibiotics will be necessary, and of the possibility that the child will need additional support.

- If fetal surgery is not an option, review the timing of delivery by 37 weeks and post-natal management. The first step should be the closure of the spinal defect within 24 hours followed by attention to hydrocephalus as indicated.

- Emphasize typical aspects of newborn care, including breastfeeding and skin-to-skin care.

- Counsel families who choose to continue the pregnancy that there are many normal aspects of pregnancy, caregiving for the newborn and parenting across the lifespan. (clinical consensus)

5. Discuss folic acid and recurrence risk.

- Reassure the parents that while NTDs are not completely understood, this birth defect was not something that was caused by their actions.

- Reassure the parents that while folic acid can help diminish the chance of a pregnancy being affected by NTD, it is not entirely preventative.

- Counsel women about their recurrence risk and review the 1991 U.S. Public Health Service guideline for daily consumption of 4 milligrams (4000 micrograms) of folic acid beginning at least one month (but preferably 3 months) before they start trying to get pregnant and continuing through the first three months of pregnancy. (Women's Health Guidelines)

Transition Guidelines

1. Provide families with a realistic, long-term orientation that includes a probable trajectory for adult function and expectations for optimal independence according to the child's abilities.
2. Provide information for families regarding long-term financial, insurance, and supportive living planning based on the child's probable trajectory into adult function.
3. Set expectations as to where individuals with Spina Bifida can access comprehensive care throughout the lifespan, including transition care.

Family Functioning Guidelines

1. Refer families who have received a prenatal diagnosis of Spina Bifida for prenatal counseling and consultation with members of a Spina Bifida multidisciplinary clinical team. Assess family dynamics and adjustment in response to diagnosis. (Prenatal Counseling Guidelines)
2. Assess for postpartum depression. Provide information about Spina Bifida, parenting, treatments, support groups, and the Spina Bifida Association. (clinical consensus)
3. Coordinate services during the transition from the hospital stay to subsequent clinic follow-up, stressing the need for ongoing multi-specialty care.
4. Teach necessary home care procedures such as post- surgical care, skin care, and clean intermittent catheterization, as needed.
5. Assess family dynamics and adjustment (e.g., post-traumatic stress disorder in parents) during infancy.
6. Refer the parents or caregivers to infant intervention and appropriate state programs (e.g., Supplemental Security Income) and financial resources as needed. Provide financial counseling if necessary. (clinical consensus)
7. Provide support and ongoing counseling as needed to parents, the child, and siblings.
8. Provide anticipatory guidance for parents regarding strengths and possible cognitive and behavioral challenges in children with Spina Bifida and their siblings.

9. Teach parents to advocate for themselves and their child when working with medical, educational, and agency staff. (clinical consensus)
10. 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).
11. Assess the family's ability to carry out medical regimens, and identify possible barriers to adherence, such as need for caregiver support and parental beliefs regarding alternative therapies.

Mental Health Guidelines

1. Assess family functioning, stressors and supports. Identify strengths and build on resources and supports that encourage resilience.
2. Provide parents with detailed information about Spina Bifida. (Prenatal Counseling Guidelines)
3. Connect families with contact information of local Spina Bifida Association (SBA) Chapters, community resources, and the SBA's National Resource Center. (clinical consensus)
(<http://spinabifidaassociation.org/chapters/>)
(<http://spinabifidaassociation.org/national-resource-directory/>)
4. Address developmental strengths and concerns through information and support. (clinical consensus)
5. Refer to early intervention services [INSERT LINK TO EARLY INTERVENTION] and the American Academy of Pediatrics. (clinical consensus) (INSERT LINK TO <https://www.aap.org/en-us/Pages/Default.aspx>)
6. Assess quality of parent-child attachment.
7. Promote effective parenting skills in stimulation, caregiving, and enjoyment of the child to optimize typical child development. (Neuropsychology Guidelines)
8. Screen for post-partum depression and post-traumatic stress disorder. (Prenatal Counseling Guidelines)

Quality of Life Guidelines

1. Consider strategies to assess and strengthen family functioning, which can be of critical importance in QOL outcomes in children. (clinical consensus) (Family Functioning Guidelines)
2. Address constipation because long-term constipation impedes the development of an effective bowel program. (clinical consensus) (Bowel Function and Care Guidelines)

Self Management and Independence Guidelines

1. Provide instruction and support to families regarding knowledge and skills needed to manage their child's Spina Bifida and related issues. (clinical consensus)
2. Provide orientation to families that include the expectation for eventual self-management and independence according to the individual's age and the status of their Spina Bifida. (Prenatal Counseling Guidelines)
3. Encourage families to expect participation in activities of daily life including tasks such as picking up toys, cleaning up, and imitative housework. (clinical consensus)
4. Evaluate and support family function. (Family Functioning Guidelines)

5. Identify and make referrals to early intervention programs. (clinical consensus) (Appendix: Early Intervention Services, Individualized Educational Plans (IEP) and 504 Plans)

Neuropsychology Guidelines

1. Provide parents with formal teaching and intervention around the development of effective parenting practices for fostering developmentally appropriate and responsive parent-child interactions. Teach parents more interactive parenting strategies, as research has shown that doing so in infancy results in significantly stronger cognitive and social language outcomes (at age 3) and better social problem-solving skills (at age 7). (clinical consensus)
2. Closely monitor infants who have undergone prenatal treatment, given the paucity of literature on their long-term outcomes.
3. Use infant development scales that assess cognition, language, motor, and social development for all infants with SBM, including those who have not been surgically treated for hydrocephalus. Adaptive behavior assessments that are interview-based are easy to complete and sensitive to growth trajectories in development.

Neurosurgery Guidelines

Patient/ Family

1. Consult with a multi-disciplinary team prior to birth to establish joint delivery plan and a plan of care. (clinical consensus)
2. Learn about regional centers that could provide evaluations for the suitability of IUMC upon prenatal diagnosis of NTD if desired. (clinical consensus)
3. Support and encourage periconceptional dietary consumption of folate to minimize the incidence of folate-related Spina Bifida.(Women's Health Guidelines)

Providers/Neurosurgeons/Spina Bifida Clinic

1. Meet with the parents of patients with fetal Spina Bifida soon after the diagnosis to discuss the impact of the Spina Bifida on the child and family. Review options with regard to continuation versus termination of pregnancy and IUMC and provide information on newborn care management. Provide prognosis for neurologic capabilities and limitations and explain the need for long-term multidisciplinary care. (clinical consensus) (Prenatal Counselling Guidelines)
2. Recognize indications for IUMC when infants are prenatally diagnosed with MMC, discuss this with families and refer them to regional centers that provide IUMC. (clinical consensus)
3. Define and disseminate quality outcomes for IUMC. (clinical consensus)
4. Encourage IUMC centers to seek, use, and continue to refine best available techniques to minimize premature delivery and other risks of IUMC.
5. Deliver babies with MMC who are being carried to term via cesarean or vaginal delivery. Babies undergoing IUMC are uniformly delivered via cesarean delivery. Despite the lack of consistent evidence of superiority there appears a clinical preference toward cesarean delivery.
6. Coordinate care with local and regional medical centers to optimize delivery, immediate care, transfer to centers with subspecialty availability and optimize early care for infant and mother. (clinical consensus)
7. Protect newborn MMC patient placode with clean, moist dressings.

8. Close new MMC within 48 hours of birth in viable newborns.
9. Surgically re-approximate the pial edges of the neural placode (“surgical neurulation”) and close the wound in sequential layers.

Mobility Guidelines

1. Assess neurologic and motor level using standardized assessment tools so there is a baseline to monitor for neurologic changes. (clinical consensus)
2. Assess multi-domain developmental milestone progress using standardized tools. (clinical consensus)
3. Refer to early intervention programs and implement physical and occupational therapy programs to optimize skill attainment in fine motor and gross motor domains. (clinical consensus)
4. Maximize motor development using good body alignment with an emphasis on trunk control as a first key goal.
5. Use the “Back to Sleep, Prone to Play” model that emphasizes postural control acquisition as the foundation of movement. Focus on antigravity muscle activity that engages the trunk extensors before the trunk flexors. Lack of prone positioning is linked to developmental delays in typical infants and therefore has an impact on children with disabilities.
6. Provide a family-centered approach and, in conjunction with the family, develop strategies to incorporate mobility within the home environment and daily routine. (clinical consensus)
7. Use casting, splinting, and orthoses to support and maintain alignment and movement. Monitor skin according to recommended guidelines. (clinical consensus) (Integument (Skin) Guidelines)
8. Collaborate with orthopedic specialists to monitor for age specific musculoskeletal problems. (Orthopedic Guidelines)
9. Encourage weight-bearing activities every day to promote bone health. (clinical consensus)

Orthopedics Guidelines

1. Perform neonatal kyphectomy, if required to facilitate skin closure.
2. Orthopedic evaluations are recommended every three months in the first year of life. (clinical consensus)
3. Consider hip imaging using ultrasound in the infant and anteroposterior pelvis radiographs after 6 months in patients with low lumbar or sacral lesions. Consider using a rigid abduction orthosis to treat hip instability, but only in children with low lumbar and sacral deformities. (clinical consensus)
4. Ponseti casting or release is recommended for clubfoot or congenital vertical talus deformities.
5. Perform spine evaluations by conducting a physical exam. Obtain scoliosis radiographs if a spinal deformity is suspected and monitor the spine for the progression of the deformity. In children who have not achieved sitting balance, perform radiographs in a supine position. Once sitting balance is achieved, perform spinal radiographs in a sitting position. (clinical consensus)
6. Consider bracing or casting when there is a documented progression of scoliosis.

Physical Activity Guidelines

1. Conduct infant motor development assessment to evaluate motor function in children with Spina Bifida to identify the most appropriate therapeutic intervention to enhance motor development outcomes. (Mobility Guidelines)
2. Provide guidance to parents and caregivers and include physical therapists in discussions about how to encourage movement and activity in their child. (Health Promotion and Preventive Health Care Service Guidelines)
3. Inform parents and caregivers of their child's right to early intervention services that include adapted physical education/activity (Appendix: Early Intervention Services, Individualized Educational Plans (IEP) and 504 Plans). Encourage parents/caregivers to request that physical activity goals be added to the IFSP, if eligible for IFSP.

Sexual Health and Education Guidelines

1. Educate parents and caregivers about the anticipated neurologic sequelae of Spina Bifida including how sexual functioning may be impacted and that sexuality is a part of life for everyone including people with disabilities. (clinical consensus)

Urology Guidelines

1. Obtain the following baseline studies within three months of birth:
 - Renal/bladder ultrasound and repeat in six months
 - Urodynamic testing
 - Serum creatinine (clinical consensus)
2. Initiate CIC and antimuscarinic therapy for the treatment of mixed incontinence when indicated based on the above results. (clinical consensus)
3. Consider the presence of a UTI when there is a fever (100.4 F / 38.0 C). In neonates less than one month of age with failure to thrive and dehydration.

Define a UTI by:

4. a positive UA, and
5. a positive urine culture (UC) on a catheterized specimen, and
6. fever (100.4 F / 38.0 C).

Define a positive Urine Analysis (+ UA) as:

7. >trace nitrite or leukocyte esterase on dip UA, and
8. >10 white blood cells/high power field (WBCs/hpf), uncentrifuged specimen, or
9. >5 WBCs/hpf, centrifuged specimen. Define a positive UC (+UC) as:
10. >50,000 colony forming units/milliliter (CFUs/mL) (sterile specimen obtained by catheter or suprapubic catheter aspirate).
11. >100,000 CFUs/mL in a clean voided specimen.

Bowel Function and Care Guidelines

1. Monitor stool frequency, consistency, and amounts.
2. Use dietary management, in particular breastfeeding if possible, as it is easier to digest and offers better restoration of the microbiome after surgery. (clinical consensus)

3. Consider dietary management (fiber and fluids) before pharmacologic adjuncts (sennoside), and/or rectal stimulants (glycerin suppositories) to manage constipation.
4. Use barrier creams to protect perineal area from breakdown as needed. (Integument (Skin) Guidelines).

Endocrine: Puberty and Precocious Puberty Guidelines

1. Monitor and document weight and length closely at every health supervision visit. Length should be measured with a length measuring board. (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. (clinical consensus)

Endocrine: Short Stature and the Effect of the Human Growth Hormone Guidelines

1. Take frequent and accurate weight, length, and occipital frontal circumference measurements during infancy and early childhood.
2. Make referrals to physical therapy to maximize range of motion, strength, and functional mobility as appropriate for the developmental age. (clinical consensus) (Mobility Guidelines)
3. Encourage breastfeeding and appropriate nutrition. (Nutrition Guidelines)
4. Discuss issues surrounding growth of children with Spina Bifida with the family. (clinical consensus)

Integument (Skin) Guidelines

1. Discuss insensate skin with parents/caregivers.
2. Discuss the risk factors that may contribute to impaired skin integrity.
3. Teach to inspect the skin for changes in color, texture, and temperature.
4. Discuss the need to check water temperature and encourage the use of a bath water thermometer.
5. Tell parents and caregivers to check for hot surfaces that have been exposed to the sun such as car seats and playground equipment.
6. Recommend the use of barrier creams to protect the skin from damage as a result of bowel and bladder incontinence.

Latex and Latex Allergy Guidelines

1. Inform parents and caregivers about latex allergy and ways to provide safe infant care while avoiding exposure to latex products.

2. Avoid using health care products that contain latex when caring for infants with Spina Bifida
3. Inform staff and families of any latex-containing products such as bottle nipples, pacifiers, teething rings, toys, and other items such as urinary catheters. (Appendix 1)

Nutrition, Metabolic Syndrome, and Obesity Guidelines

1. Assess weight, height and occipital frontal head circumference at every clinical encounter. (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.
 - 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.
 - 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 seven-10 days) to ensure enough will be available once the infant has surgery.
 - Advocate for babies to be hospitalized in close proximity to their mothers to facilitate breastfeeding.
 - Provide mothers with information about accessing breast milk banks and to plan for situations where she cannot provide the breast milk herself.
 - 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.
 - 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).¹⁹
 - 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.
 - Support mothers to thicken their breast milk to prevent aspiration.
 - 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.
 - Highlight that the baby's transition from drinking breastmilk to eating solid food can cause constipation.
 - Close multi-disciplinary follow up is indicated for infants with slow weight gain and failure to thrive. (clinical consensus)

Sleep Related Breathing Disorders Guidelines

1. Screen for SRBD signs and symptoms in all infants with NTD at each health care maintenance visit using available standardized questionnaires.
2. Encourage that all symptomatic infants or those with additional risk factor for OSA (high spinal lesion, small cervicomedullary arachnoid space, or severe Chiari malformation) undergo a formal evaluation for SRBD with overnight polysomnography or be referred to a specialist with expertise in sleep-related breathing disorders.
3. Refer all infants with documented SRBD referred to appropriate specialists with expertise in SRBD (pediatric pulmonologist or sleep specialist), neurosurgeon, and/ or otolaryngologist) for ongoing management.
4. Conduct periodic cardiac evaluations on infants with documented SRBD and hypoxemia to assess for pulmonary hypertension and cor pulmonale.