



Spina Bifida:
*Your Guide to
a Healthy Life*

Sleep-Related Breathing Disorders

For ages 0-18+

***Adapted from Guidelines for the Care of
People with Spina Bifida, 2018***

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Introduction



Sleep Related Breathing Disorders (SRBD)¹ affect an estimated 60-80 percent of people with myelomeningocele – and this is considered a low estimate. A person with an SRBD has trouble getting enough oxygen while sleeping. When there is a lack of oxygen or a buildup of carbon dioxide in the blood during sleep, the body’s usual response is to wake up or take deeper breaths. However, people with myelomeningocele may lack these typical protective responses.

This is an important issue because untreated and undiagnosed SRBD can lead to cognitive, psychological, and cardiovascular problems – and even death. Chronic SRBD is the cause of death in 13-16 percent of patients with myelomeningocele. Sudden unexplained death in infants (0-19 months of age), thought to be related to SRBD, has also occurred.

Some causes of SRBD in people with myelomeningocele may require surgery. Shunt revision or Chiari decompression surgery may help but they do not always fix all the symptoms, and people may still need help breathing after the surgery.

Screening for Sleep Related Breathing Disorders

Because SRBD is so widespread, everyone with myelomeningocele should be routinely screened. Since identifying these problems in a clinic visit can be challenging, the recommendation is that overnight “sleep studies” (known as overnight observed polysomnography) be performed in all people with myelomeningocele – whether or not they have symptoms. If a formal sleep study isn’t possible, overnight measuring of the blood’s oxygen content (pulse oximetry) may be used to detect moderate to severe SRBD.

¹ The types of SRBD among people with myelomeningocele include:

Central apnea – pauses in breathing regulated by the brain

Periodic breathing –at least 3 central apneas separated by breaths of no more than 20 seconds

Obstructive apnea/hypopnea – partial or complete airway obstruction that interferes with breathing

Central hypoventilation – abnormally shallow or slow breathing that causes oxygen levels to decrease and carbon dioxide levels to increase in the blood

0-11 Months

1. Ask your baby's healthcare provider about screenings for SRBDs at your regular check-ups.
2. Monitor your baby for signs of breathing difficulties, such as: stridor (high-pitched wheezing); apnea (pauses in breathing) and problems with feeding.
3. If your baby has signs of SRBD or is at greater risk, ask your provider about an overnight sleep study and a referral to a specialist for ongoing management.
4. Ask your provider about other tests your baby might need if diagnosed with SRBD.

1-2 Years

1. Ask your child's provider about screenings for SRBD at your regular check-ups (well-child visits).
2. Monitor your child for signs of breathing difficulties, such as: stridor (high-pitched wheezing); apnea (pauses in breathing) and problems with feeding.
3. If your child has signs of SRBD or is at greater risk², ask your provider about an overnight sleep study and a referral to a specialist³ for ongoing management.
4. Ask your child's providers about healthy sleep habits and what you can do to promote these in your child.





3-5 Years

1. Talk with your child's providers about any concerns you have with your child's sleep. Signs of SRBD in children can include mouth breathing, inattentiveness, hyperactivity, and delayed growth.
2. Talk with your child's providers about any concerns with their breathing. Be on the lookout for shortness of breath, snoring, choking, irritability, and episodes of cyanosis (when skin turns blue due to the lack of oxygen in the blood).
3. If your child has signs of SRBD or is at greater risk², ask your provider about an overnight sleep study and a referral to a specialist³ for ongoing management.
4. Ask your child's providers about yearly screenings for SRBD.
5. Ask your child's providers about how to monitor your child's breathing so you can be on the lookout for early symptoms or changes.

² Risk factors for SRBD include a high spinal cord lesion, abnormal brain stem structure or function, complications of a Chiari malformation, abnormal airway or lung function/structure, and obesity.

³ A specialist that would follow a patient for SRBD could be a pediatric pulmonologist, sleep medicine specialist, neurosurgeon, or otolaryngologist (ENT).

6-12 Years

1. Talk with your child's provider about any concerns you have with your child's sleep. Signs of SRBD in children can include mouth breathing, poor school performance, inattentiveness, hyperactivity, and delayed growth.
2. Talk with your child's providers about any concerns with their breathing. Be on the lookout for shortness of breath, snoring, long pauses in breathing, gasping/choking at night, being very sleepy during the day, mood changes, difficulty thinking, and irritability.
3. If your child has signs of SRBD or is at greater risk², ask your provider about an overnight sleep study and a referral to a specialist³ for ongoing management.
4. Ask your child's providers about yearly screenings for SRBD.
5. Ask your child's providers about how to monitor your child's breathing so you can be on the lookout for early symptoms or changes.

13-17 Years

1. Ask your teen's providers about yearly screenings for SRBD.
2. Encourage your teen to ask questions about their sleep patterns with their provider.
3. Talk with your teen's provider about any of your concerns with their breathing. Be on the lookout for shortness of breath, snoring, long pauses in breathing, gasping/choking at night, being very sleepy during the day, mood changes, difficulty thinking, and irritability.
4. If your teen has signs of SRBD or is at greater risk², ask your provider about an overnight sleep study and a referral to a specialist³ for ongoing management.
5. Ask your teen's provider about conditions that either contribute to or are the result of SRBD, such as hypertension, obesity, and scoliosis.
6. Ask your teen's providers to help you educate your teen about SRBD - how to recognize it, and how it can affect their quality of life.



18+ Years

1. Ask your providers about yearly screenings for SRBD.
2. Talk with your providers about any concerns with breathing. Be on the lookout for shortness of breath, snoring, long pauses in breathing, gasping /choking at night, being very sleepy during the day, mood changes, difficulty thinking, and irritability
3. Ask your provider about conditions that either contribute to or could be the result of SRBD, such as hypertension, obesity, and scoliosis.
4. If you have signs of SRBD or are at greater risk², ask your provider about an overnight sleep study and a referral to a specialist³ for ongoing management.
5. Ask your providers about SRBD - how to recognize it, and how it can affect your quality of life.
6. Because you might not notice changes in your own breathing while sleeping, talk with family members, friends, partners, or spouses - anyone who might observe you sleeping. Ask them to watch for problems such as pauses in your breathing and worsening snoring.