Sleep Apnea

WHAT IS OBSTRUCTIVE SLEEP APNEA (OSA)

Sleep apnea is a problem with breathing during sleep that can lead to decreased oxygen levels and frequent brief wake-ups that are typically not remembered. There are two main types of sleep apnea: obstructive sleep apnea (OSA) and central sleep apnea (CSA). OSA is the most common and occurs when the airway is physically blocked. CSA is much less common and occurs when the brain does not send the correct signals to the muscles that control breathing.

Individuals with Down syndrome are more likely to have OSA than individuals without Down syndrome. Studies have suggested 53-76% of children with Down syndrome and more than 80% of adults with Down syndrome have OSA. This may be due to factors that tend to occur at higher rates in individuals with Down syndrome such as:

- facial structure differences
- narrow airway in the nose and throat
- low muscle tone
- poor coordination of airway movements
- obesity

WHY TREAT OSA

Untreated OSA in individuals with Down syndrome can lead to unwanted behaviors and decreased language, memory, and emotional control. Children may have tantrums, be less willing to use words to communicate, or have trouble learning new skills. Adults may be less engaged in conversations and normal activities, forget parts of their usual routine, or have difficulty following directions. OSA also increases the risk of cardiovascular disease (Shott et al., 2006).

HOW TO DIAGNOSE OSA

SLEEP STUDIES

The American Academy of Pediatrics recommends all children with Down syndrome have a polysomnography (PSG), or a sleep study, by 4 years of age. The PSG consists of a night of observed sleep during which brain waves, the oxygen level in the blood, heart rate, breathing, and eye and leg movements are measured. Children who are unable to have a PSG due to lack of access or inability to tolerate the conditions might have a home sleep study or home pulse oximetry.

Symptoms of sleep abnormalities may include all the following, though some children with OSA may not have any of these symptoms:

- restless sleep
- snoring
- gasping noises
- heavy breathing
- apneic pauses (a pause in breathing)
- frequent waking during the night
- daytime sleepiness
- excessive napping
- unusual sleep positions (such as sitting upright or keeping the head and neck tilted backward)
- trouble getting out of bed

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TREATMENTS FOR OSA

TONSIL AND ADENOID REMOVAL

The most common treatment in children is adenotonsillectomy (surgical removal of tonsils and adenoids). Unfortunately, up to half of children with Down syndrome experience OSA that continues even after surgery, though most children will see a decrease in OSA severity.

CPAP/BIPAP USE

Continuous positive airway pressure (CPAP) or bilevel positive airway pressure (BiPAP) therapy is often used as a secondary treatment after surgery. CPAP and BiPAP machines are typically life-long treatments.

- **CPAP:** A machine that delivers a steady stream of air through a flexible tube to a mask sealed around a person's nose and mouth. The airstream pushes against any obstructions, maintaining an open airway for breathing. CPAP machines are primarily used to treat OSA.
- **BiPAP:** A machine used for individuals who cannot tolerate CPAP machines and to treat CSA. There is a higher pressure when breathing in and a lower pressure when breathing out.

OTHER TREATMENTS

- Hypoglossal nerve stimulation which involves an implanted medical device that electrically stimulates tongue movement with breathing
- Dental devices worn at night that push the lower jaw forward
- Reaching and maintaining a healthy weight
- A combination of the medications Atomoxetine and Oxybutynin which have shown an improvement in OSA severity of about 50% in children with Down syndrome (Combs et al., 2023)

All options should be discussed with a doctor to determine which is best for you or your loved one. Remember: This resource can be a helpful tool to better understand and communicate with your healthcare provider about OSA. However, a research study found that caregivers were usually unable to accurately predict whether their loved one had OSA, so even if you do not notice the symptoms above, it is important to schedule regular sleep studies throughout the lifespan (Shott et al., 2006).

Thank you to Daniel Combs, MD, Assistant Professor of Pediatrics and Medicine at the University of Arizona, who reviewed this resource for accuracy.

REFERENCES

Combs D, Edgin J, Hsu C-H, et al. The combination of atomoxetine and oxybutynin for the treatment of obstructive sleep apnea in children with Down syndrome. J Clin Sleep Med. 2023;19(12):2065-2073.

Shott SR, Amin R, Chini B, Heubi C, Hotze S, Akers R. Obstructive sleep apnea: Should all children with Down syndrome be tested?. Arch Otolaryngol Head Neck Surg. 2006;132(4):432-436. doi:10.1001/archotol.132.4.432

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Obstructive Sleep Apnea (OSA) Symptom Checklist

Below are symptoms of OSA. Most individuals are not aware they are exhibiting symptoms during sleep, so it can be helpful to have a caregiver observe their sleep to help determine if the symptom is occurring. In the "Notes" section, record the date of onset, frequency, and severity of the symptom. Share this completed checklist with your healthcare provider.

Today's date: _____

Date of last sleep study: _____

DURING SLEEP

- ☐ **Snoring**
  Notes: _____
- ☐ **Gasping noises**
  Notes: _____
- ☐ **Heavy breathing**
  Notes: _____
- ☐ **Pauses in breathing**
  Notes: _____
- ☐ **Frequent waking**
  Notes: _____
- ☐ **Unusual sleep positions** (such as sitting upright or keeping the head and neck tilted backward)
  Notes: _____

DURING WAKEFULNESS

- ☐ **Difficulty waking up in the morning after a full night of sleep**
  Notes: _____
- ☐ **Daytime sleepiness**
  Notes: _____
- ☐ **Excessive napping**
  Notes: _____
- ☐ **Decreased language or other forms of communication**
  Notes: _____
- ☐ **Decreased emotional control**
  Notes: _____
- ☐ **Trouble learning new skills**
  Notes: _____
- ☐ **Increased forgetfulness**
  Notes: _____

Remember: This checklist can be a helpful tool to communicate any concerns with your healthcare provider. However, a research study found that caregivers were usually unable to accurately predict whether their loved one had OSA, so even if you do not notice the symptoms above, it is important to schedule regular sleep studies throughout the lifespan (Shott et al., 2006).