



DID YOU KNOW?

Obstructive sleep apnea is estimated to affect about 4% of men and 2% of women in the general population; however, it is generally believed that this is under-reported.

Sleep disorders occur more frequently in people with Down syndrome. Research suggests that obstructive sleep apnea occurs in at least 50% of this population

Sleeping difficulties are also increasingly likely in adults with Down Syndrome as they progress through the stages of dementia.

Sleep disorders are common in autism, with prevalence rates ranging from 44% to 83%¹.

Sleep Apnea

Sleep problems such as sleep apnea (temporary pause in breathing), insomnia (inability to sleep), or night awakenings are conditions that people with intellectual or developmental disabilities (IDD) commonly report. These conditions generally occur more often in people with IDD than in the general population. Anywhere from 35% to 90% of people with IDD reportedly experience a sleep problem².

Obstructive sleep apnea syndrome, or sleep apnea, is a type of sleep disorder that is commonly seen in people with IDD. Sleep apnea is especially common in people with Down syndrome, Autism Spectrum Disorder, and William's Syndrome. ***People with sleep apnea periodically stop breathing during deep sleep. Many people with sleep apnea do not realize they have it.***

In people with sleep apnea, the throat muscles relax and block the airway during sleep. The brain signals the body to increase its efforts to breathe which in turn briefly awakens the brain so that the airway can stiffen and open the throat. Efforts to breathe then decreases again and the brain goes back to sleep. These interruptions in sleep can happen hundreds of times per night, affecting deep sleep or REM cycles. People with sleep apnea may not get enough oxygen during sleep and probably don't sleep soundly.

Sleep disturbances are associated with reduced attention, poor impulse control, difficulties with daytime functioning, poor mood and behavior regulation, and impaired memory³. The negative effects of sleep deprivation also include increased stress response, altered immune system functioning, depression, hyperthyroidism and other health conditions.

¹Malow, BA, MD, et al (2006). Impact of Treating Sleep Apnea in a Child With ASD. *Pediatric Neurology*, 34(4), 325-328.

²Doran SM, Harvey MT, et al (2006). Sleep and dev. dis.: assessment, treatment and outcome measures. *Ment Retard*, 44(13), 13-27.

³Esbensen, AJ. Sleep problems in adults with Down syndrome (2016). *JIDR*, 60(1), 68-79.

Risk Assessment

Sleep apnea is commonly seen in people with certain conditions like Down syndrome, Autism Spectrum Disorder and William's syndrome as well as other intellectual and developmental disabilities.

Risk Factors

- Excess weight/Overweight
- Narrowed airway due to enlarged tonsils or adenoids
- High blood pressure
- Physical traits: large neck of 17 or more inches for men and 16 or more inches for women, small throats, small jaw or large tongue.
- Chronic nasal congestion
- Increased age
- Smoking, diabetes, or asthma.
- Being male

Signs and Symptoms

- Excessive daytime sleepiness
- Abrupt awakenings accompanied by gasping or choking; frequent night wakening
- Loud snoring
- Awakening with a dry mouth or sore throat
- Morning headaches
- Periods of apnea (not breathing) often noted by others
- Poor concentration or forgetfulness
- Mood changes, depression or irritability
- Difficulty concentrating during the day
- Nighttime sweating

Complications and health risks associated with sleep apnea

- Increased risk of abnormal heart rhythms (arrhythmias)
- Greater risk of coronary artery disease, heart attack, heart failure and stroke
- High blood pressure
- Impaired glucose tolerance and insulin resistance
- Frequent nighttime urination
- Depression
- Menstrual irregularities
- Some research has found a connection between obstructive sleep apnea and glaucoma

Snoring?

When people sleep, the throat muscles relax. This leads to a narrowing of the throat and airway. Snoring itself indicates that the airway is not open enough or is blocked. The sound of snoring is made when the body is trying to force air through that blocked air passage. Approximately 10-30% of adults snore. In most cases, snoring causes no serious health risks. However, for about 20% of those who snore, ***very loud nightly snoring can be a sign of obstructive sleep apnea syndrome or sleep apnea.*** Anyone with loud snoring, or periods when they appear to stop breathing, should be evaluated by their health care provider.

Prevention and Management

Possible Treatments for Sleep Apnea

- Losing weight
- Sleeping in the side position
- Using oral devices (similar to a sports mouth guard) that help maintain an open airway by stabilizing the lower jaw, tongue or mouth.
- Using a Continuous Positive Airway Pressure (CPAP) or a Bi-Level Positive Airway Pressure (BiPAP) machine.

If a sleep disorder is suspected

1) It may be worthwhile to first assess the environment. Sometimes the source of sleep troubles for people with disabilities is something in the environment that they may not recognize or be able to communicate¹.

Lie in the person's bed (with their permission!)

- Is the mattress lumpy? Does it smell bad? Or maybe the sheets are itchy and uncomfortable.
- Is there light shining in your face from the window? Or a flickering light like from a TV?
- Are loud noises easily heard?

2) Contact the person's Health Care Provider to discuss sleep concerns.

3) In most cases an official diagnosis is needed before ordering equipment (e.g. CPAP) from insurance.

¹ <http://www.reifpsychservices.com/sleep-hygiene-disabilities/>

CPAP and BiPAP Systems

CPAP and BiPAP systems help people breathe more freely and restfully. A Continuous Positive Airway Pressure (CPAP) machine delivers a predetermined level of pressure which helps to keep the airway open under continuous pressure. A Bi-Level Positive Airway Pressure (BiPAP) machine delivers two levels of pressure, one when the individual breathes in and one when the individual breathes out.



Each program is expected to have an individualized protocol for people using a CPAP or BiPAP machine. Guidance and samples are listed on page 4.

General Guidance:

- Regularly clean the machine and change the water.
- Always use distilled water in the humidifier chamber.
- Empty the humidifier chamber completely prior to any movement or transportation of the machine.
- Machine parts do not go in the dishwasher.

Usage

- If the machine is not functioning correctly or the power cord or plug is damaged do not attempt to repair it and do not use.
- The mask may be uncomfortable at first. Help people get used to the mask by wearing it for short periods of time while awake. Help familiarize people by explaining machine parts, off/on switches, etc.
- If someone develops a nasal or ear infection, or other illness, it may be further irritated by use of the machine. Contact the health care provider for further instruction.

Training

- Staff do not need to be MAP Certified to manage the CPAP or BiPAP machine. However, when oxygen is being used with the machine, direct care staff monitoring and assisting with the machine must be MAP certified and trained in the use of oxygen.
- Training in use of the equipment is usually provided by the respiratory equipment supply company or RN.

MA DDS Guidelines and Resources

DDS CPAP/BiPAP Use Guidelines

Each program is expected to have an individualized protocol in place for any person using a CPAP or BiPAP machine. The individualized protocol must include at least:

- A copy of the Health Care Provider (HCP) order
- Reason for use
- How to operate equipment including detailed responsibilities during various parts of the process:
 - Bedtime
 - Morning
 - Weekly and biweekly cleanings
- How to clean and maintain equipment according to manufacturer's instructions
- When and how to order new parts from the medical supply company
- How use is documented
- Plan for assuring compliance and, if necessary, desensitization to equipment
- Frequency of monitoring and observation during use
- Clear instruction on what to report to supervisor and HCP (Health Care Provider):
 - Any redness or facial sores
 - Refusal to wear face mask/nasal cushion or to use CPAP/BiPAP
 - Consistent runny nose or cold symptoms
 - Changes in sleep pattern, continual waking overnight or individual unable to tolerate the mask or the machine.
 - No improvement in the following symptoms: daytime sleepiness, morning headaches, poor concentration and forgetfulness, mood changes, anxiety, irritability, depression.

Resources

- American Sleep Apnea Association: www.sleepapnea.org
- **DDS Guidelines and Protocols:** All of the DDS CPAP/BiPAP guidelines and protocols can be accessed here: <https://www.mass.gov/lists/health-and-safety-guidelines#cpap/bipap-use->
 - CPAP SP Device Cleaning
 - BiPAP SP Device Cleaning
 - Blank CPAP Supply Replacement Schedule
 - CPAP Supply Replacement Schedule
 - Guidance on Management of Diagnosis of Sleep Apnea
 - L38 Interpretation Recommendations
 - Sample Individualized Health Care Protocol for Management of Sleep Apnea
 - Supportive Protective Device

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