



# Complex Child E-Magazine

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## **Treating Obstructive Sleep Apnea in Children with CPAP or BiPAP**

During infancy, my almost four-year-old with severe cerebral palsy started jerking her legs and crying while falling asleep. She seemingly slept soundly once asleep, so she was placed on several anti-seizure medicines to stop these seizure-like movements. When she continued to have difficulties on anti-seizure medicines, she was referred to a Sleep Clinic and at fourteen months old was diagnosed with Sleep Apnea based on her physical exam and history. Shortly thereafter she was found to have Obstructive Sleep Apnea (OSA) after a Nocturnal Sleep Study.



It is estimated that two to three percent of children suffer from Obstructive Sleep Apnea (OSA) or interrupted breathing during sleep.<sup>1</sup> OSA occurs when the child's attempts to breathe during sleep are challenged by an obstruction in the airway such as the tongue falling back and blocking the airway. OSA can involve complete airway obstructions

(apneas) or partial airway obstructions (hypopneas). It typically results in long pauses in breathing, arousal, and/or significant reduction in oxygenation.

In children, OSA is most commonly caused by adenoids and/or tonsils that are relatively too large given the size of the airway; therefore, the first line of treatment is removal of the tonsils and adenoids. However, in some cases, OSA can be caused by additional conditions including but not limited to sedatives, neurological disorders (which create changes in muscle tone), or facial structures (which create a narrow airway).<sup>2</sup> Often attempts will first be made to treat the potential underlying conditions, such as weaning off of a sedative, before surgery is considered. If surgical treatments have not created or are not likely to create long-term positive outcomes, a trial of Continuous Positive Airway Pressure (CPAP), a non-invasive breathing treatment used with inpatient children and most typically used outpatient for adults with OSA, will be suggested.

My daughter has very small tonsils and adenoids but the founder of the Sleep Clinic insisted that any extra space in her crowded airway (her tongue is too large for her small jaw) would make a difference. However, two Ear, Nose and Throat Specialists felt that her difficulties were likely related to her low tone and that the minor benefit of surgery did not outweigh the risks. For this reason, she was weaned off her sedating anti-seizure medicines, had another Sleep Study to determine a CPAP pressure that would stop her airway from closing, and started CPAP when she was around 18 months old.

### **CPAP/BiPAP Treatment**

CPAP is a breathing treatment that uses a constant flow of air at a high pressure to prop open a child's airway and keep it free from obstructions. A CPAP machine administers air at a single prescribed pressure and a Bilevel Positive Airway Pressure (BiPAP) machine administers air at two different prescribed pressures: a higher pressure for inhaling and a lower pressure for exhaling. CPAP and BiPAP machines often have a built-in humidifier which helps warm the air and improve comfort.

A BiPAP machine is used when a child is not able to tolerate CPAP because of difficulty exhaling against the positive air pressure. It can also be used when a child exhibits shallow breathing because it is more sensitive to subtle changes in breathing. Both CPAP and BiPAP pressures are determined during a special type of Sleep Study that records the effects of different air pressures on the child's respiratory functions. Typically, the air pressure that results in the least number of apneas is prescribed.

My daughter used CPAP for three months but she was swallowing air and her airway was still closing partially. She was switched to BiPAP to help better address her shallow breathing. Her BiPAP pressures were initially based on her CPAP pressures, although they were ultimately checked with two additional BiPAP sleep studies approximately a year apart. Switching to BiPAP made noticeable differences. She no longer needed suctioning every morning and her red blood cell count started to decrease after rising in response to chronic reduced oxygen from her OSA.

### CPAP/BiPAP Interface

CPAP/BiPAP is delivered through tubing and into a mask that is attached to the child's face with a headgear. Nasal CPAP masks, which send the air through the sinuses and into the airway, are most often used with children; however, full-face masks, which cover both the nose and mouth, are sometimes used with children who breathe through their mouths if a nasal mask with a chin strap to keep the mouth closed is not tolerated. A full-face mask is not typically suggested for children who have reflux because of the risk of aspiration or asphyxiation if the child vomits while wearing the full-face mask.



Because relatively few children are prescribed CPAP/BiPAP treatments for sleep apnea, there is only one FDA-approved nasal CPAP mask specifically designed for children aged seven and up. This makes fitting a mask for a child very challenging because it requires downsizing an adult mask and headgear. If the mask and headgear used during the Sleep Study effectively administered the air pressure without significant leaks or discomfort to the child then that interface will be prescribed for the child.

However, in some cases the mask may not provide an adequate seal and a child will need to visit a Durable Medical Equipment (DME) provider who specializes in providing sleep equipment in order to try on a large variety of small or petite sized adult nasal masks and adjustable headgears to get the correct fit. In some cases, particularly for the child with small features, if a good fit cannot be established the CPAP/ BiPAP pressure may be adjusted higher to compensate for the presence of leaks. After the initial CPAP/BiPAP Sleep Study and mask fitting, the provider will also supply the prescribed CPAP/BiPAP machine, tubing and other supplies, replacing them as needed or, more commonly, in intervals specified by insurance coverage for those items.

My daughter breathes through her nose and has reflux so a nasal mask was chosen for her. She fought the petite nasal mask used during the CPAP Sleep Study and it had such a poor fit around her small facial features that she was immediately refitted at the Sleep Clinic days after her titration study for nasal pillows (soft silicone cushions that fit inside the nose). She tolerated these a little better and we then ordered them from our DME provider. I cut and used velcro to resize the headgear down to her size and hoped it would work. Less than a year into her treatment, the design of my daughter's nasal pillows changed so her mask no longer fit well. I searched online and found another brand of nasal pillows that were petite enough to fit her nostrils. Her DME provider ordered them and my daughter used them with her original velcro-resized headgear.

### **Adjusting to BiPAP/CPAP**

It is likely to take time and effort for a child to get used to using a CPAP/BiPAP mask and headgear. The nasal mask and headgear need to be fairly snug in order to maintain an effective seal against leaks around the nose. If they are too snug, red marks or sore areas can be created. Lubrication with a non-petroleum gel and/or strap covers may be needed to prevent skin breakdown.

The restrictive mask and headgear can also be very claustrophobic, limiting the child's view when it is in place. Indeed, for particularly young children who are not likely to notice the improved energy provided by better sleep using the CPAP/BiPAP, having to wear the cumbersome equipment can be very upsetting and equated to strapping on a primitive torture device. Therefore, gradually exposing a child to the CPAP/BiPAP mask is recommended. For example, some Sleep Clinics will provide a nasal mask prior to the titration study so that the child can see the mask ahead of time and get used to trying it on without the air pressure.

After the CPAP/BiPAP Sleep Study and once the equipment is brought home, it is also recommended that parents incorporate putting on the mask into the child's typical bedtime routine. Although it is often easier to put the mask on after the child is asleep, it can be very frightening for a child to wake up suddenly with her mask on unexpectedly. Strategies for helping the CPAP/BiPAP become part of your child's routine sleep pattern may need to be modified according to the child's developmental level. See these fliers

[[http://www.seattlechildrens.org/our\\_services/clinical\\_services/sleep\\_disorders\\_program/resources.asp](http://www.seattlechildrens.org/our_services/clinical_services/sleep_disorders_program/resources.asp)] for suggestions for different developmental levels.

With young children extra creativity may also be needed. For example, it may be helpful to pretend the mask and/or tubing turns the child into a particular character (space creature) or animal (such as an elephant) and to read the child a story about that character or animal when the child has the mask, headgear and tubing on and is starting her treatment in bed. In addition, placing an extra mask on a favorite doll or stuffed animal may also encourage the child to wear his/her mask. Small prizes may also need to be given to reward a child for wearing the mask longer and longer each night.

It may also take time for a child to get used to breathing with the air pressure. Even with a built-in humidifier, the air can be very drying so irrigation with a saline spray prior to beginning CPAP/BiPAP can be helpful. Nasal congestion can also disrupt the flow of air and make the CPAP/BiPAP very uncomfortable; therefore, saline sprays, nasal suctioning, and/or nasal decongestants may be needed to increase the comfort and effectiveness of the CPAP/BiPAP treatment with respiratory illness.

In addition, a child who typically breathes through his nose may open his mouth in response to the air pressure, causing a significant leak that reduces the effectiveness of the CPAP/BiPAP. When this happens saliva can be forced out at the same time, causing the child to foam at the mouth and later develop a very dry mouth or “cotton mouth.” This might be very disturbing to the child so gradual exposure to the air pressure at increasing intervals of time (with or without a reward system) may be needed to help the child learn to tolerate the air pressure and keep her mouth closed. If a child is not able to keep her mouth closed a chin strap may be added and placed over the headgear and that may also require some additional adjustment time.

My daughter initially didn't like the CPAP/BiPAP but she tolerated it when she was really drowsy. However, just months into treatment after she was weaned off her more sedating anti-seizure medicines, she started to violently fight her BiPAP and became very skilled at dislodging it whenever she was awake, even with arm immobilizers on. No matter what we tried she spent every moment she was awake fighting the BiPAP and would not fall asleep with it on so we were forced to break the cardinal rule and put her mask on after she was asleep.

When we did this she slept with it on for four hours straight and then fought it the rest of the night. At some point we would end up taking it off and then have to deal with wakeups every one to two hours after that. Although we were ready to give up on using the BiPAP, continued decreases in my daughter's red blood cell counts encouraged us to keep using it. We really felt awful forcing her to wear something she hated so much but we could not give up on it completely without facing other serious risks like strokes, high blood pressure, and heart disease.

Almost two years into treatment, with a new mask and a pressure change, she started to be able to keep her BiPAP mask on for most of the night. We'd still have to adjust the

mask after it shifted in her sleep or she woke up--it is hard to determine which comes first since we just discover it blowing air into her eyes, hair, or mouth or find it around her neck. Unless she had nasal congestion, she would sometimes fall asleep a little easier with it on than with it off. She cannot use nasal decongestants because of her chronic kidney failure so unfortunately when she is really stuffy we cannot use the BiPAP.

### **Unexpected Problems with CPAP/BiPAP and Preexisting Conditions**

When my daughter was almost two years old, she was still crying for hours to sleep every night while jerking her legs. She had a BiPAP Sleep Study that indicated a slightly more effective pressure for her. However, the BiPAP Sleep Study suddenly also indicated that she had 731 leg movements in a seven hour period. We realized then that her former anti-seizure medicines probably masked her leg movements in the previous sleep studies, so her Sleep Specialist agreed to trial a Restless Leg Syndrome drug that finally stopped the hours of crying herself to sleep while jerking her body.

The summer before she turned three years old she started experiencing severe abdominal pressure from swallowing too much air while using her BiPAP, which caused her to break the valves and plastic rings on her button feeding tube. Because we were concerned that her BiPAP pressure was too high, she had another BiPAP Sleep Study to check the pressure. During the BiPAP Sleep Study the technicians acknowledged that she had a leaky mask during her last two studies and a higher pressure was most likely prescribed to compensate for the leaks. Because there was no leak in her current mask, the pressure may actually have been too high as soon as she switched nasal pillows. Her BiPAP pressure was reduced after the Sleep Study and all of a sudden my daughter tolerated the mask more and stopped breaking her button feeding tube. Although we still had to wait until she fell asleep to put her BiPAP mask on, she did not bury her head in the bed as much to get it off and actually could fall asleep again with it still on as long as we used the Ramp function on her BiPAP, which starts her BiPAP at a lower pressure and slowly increases it to the prescribed pressure.

The fall after my daughter turned three her sleep issues started to get worse again. She started to wake up every hour, even with her BiPAP in place, and she started to cry again with leg spasms both when she woke up and also when she tried to fall asleep during the day. Her anti-seizure medicine was changed again because she was still experiencing seizure-like startles during the day. Her difficulties continued and this spring another Sleep Study determined the leg spasms were not related to her sleep apneas, Restless Legs Syndrome, or seizures. As a result, she was weaned off the Restless Legs Syndrome medicine she had been using for 18 months in case it was contributing to her difficulties.

Her Sleep Specialists agreed that her movements were painful so another anti-seizure medicine that is also sometimes used for pain associated with Restless Legs Syndrome was added. The changes in her medicines seemed to help her sleep for longer stretches again. Although it is now harder for her to fall asleep for the night, once she is asleep she

seemingly sleeps deeply and does not fight her BiPAP mask much at all. Some nights she even keeps it on for eight hours straight, sleeping through leaks and repositioning. Other nights if her mask shifts and wakes her after a particularly long period of sleep she will be rejuvenated and have difficulty falling asleep again.

### **Between a Rock and a Hard Place**

In an ideal world given enough time, your child will get used to sleeping with her CPAP/BiPAP on all night every night and sleep-deprived parents will finally catch up on sleep lost before the treatment began. However, a child's reaction to this treatment is never simple and, particularly for children with complex medical issues, often there are additional influences on sleep that also need to be addressed. Indeed, if my daughter's story demonstrates anything, it is that CPAP/BiPAP is not always an instant fix for OSA in children. Sleep patterns can change based on other unexpected conditions in children with complex problems, such as additional sleep disorders, seizures, illness, and pain and those conditions can compromise treatment efforts.

Furthermore, because of the limited equipment available for use by children there are challenges associated with both finding an appropriate mask with a correct and stable fit and finding the CPAP/BiPAP pressure to adequately address the OSA. That is, a poor mask fit combined with an inappropriate pressure can undermine treatment efforts and contribute to unexpected setbacks in a young child's compliance with treatment. Given the increasing number of children who need to use CPAP/BiPAP on an outpatient basis, more equipment should be designed soon to help address these challenges.

Like many other parents whose children need to use CPAP/BiPAP, we frequently feel torn about using the treatment. After over two years of use, my daughter probably still feels like her BiPAP is a medieval torture device and the fact that she has to wear arm immobilizers to keep her from pulling it off only solidifies this perception. We hate the fact that the mask itself sometimes disrupts her sleep when it shifts and constantly hope that some sleep equipment manufacturer will design the perfect mask and headgear for her.

Our struggles using the equipment are mitigated by the clear stabilization of her Red Blood Cell count, which stares at us on paper with every lab draw. In fact, it was probably easier for us than most parents to start using CPAP/BiPAP, having concrete evidence that without it she would be at risk for strokes and other health issues that could take away the skills she has worked so hard to gain. For this reason, we continue to try to stay grounded between a rock and a hard place.





*Erin is a stay-at-home Mom to Brooke, a very sweet, determined, non-verbal, non-mobile and 100% G tube fed child. Brooke suffered severe oxygen loss and reduced blood flow around the time of her birth, which caused chronic kidney failure, severe brain damage, microcephaly, cortical visual impairment, mixed cerebral palsy, sleep apnea, epilepsy, and reflux. Erin has also been blessed with two very caring and entertaining siblings for Brooke, five-year-old Katherine and one-year-old Ethan.*

*Erin documents how Brooke interacts with her siblings on Adapted World at <http://adaptedworld.wordpress.com>*

*Erin has a PhD in Clinical Child Psychology and although she is currently not practicing she draws upon her experience when trying to ensure Brooke obtains the services she needs.*

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<sup>1</sup> JC Lumeng and RD Chervin. "Epidemiology of pediatric obstructive sleep apnea." *The Proceedings of the American Thoracic Society* 2008;5:242-52.

<sup>2</sup> J Chan, *et al.* "Obstructive sleep apnea in children." *American Family Physician* 2004;69:1147-54.