

CPAP (Children’s Positive Airway Pressure) Program Newsletter Spring/Summer 2022



Camping With a Sleep Machine

Lots of families like to spend time camping during school breaks to connect with nature and each other. But what about camping with CPAP, BiPAP™, or a home ventilator, since these machines run on electricity?

Don’t worry—there are options for bringing your child’s sleep machine with you:

1. Find a campsite with power. This option makes things simple because all you need is an extension cord to power the CPAP. Another advantage is that this option allows you to use the humidifier. To be aware of—campsites may charge extra for electricity you use and these sites may book early. This is the best option for BiPAP™ machines and ventilators, since they use more electricity.
2. Purchase a rechargeable battery. Batteries are available online from companies like Amazon or CPAP stores and cost about \$300 and up. They are not covered by insurance. Make sure the battery works with your child’s machine model. Heated humidity will drain the power much faster. You can still use the humidifier and water, but have the heat turned off for cool humidity. Without heated humidity, a battery will typically last from 8 to 24 hours, depending on the settings and the battery. **This option also allows for your child to use their sleep machine if you have a power outage.** Consult the reviews for the battery you’re considering. Once you’ve purchased one, it would be good to do a trial run at home to see how many hours it lasts. If your child has a home ventilator, additional battery packs can be purchased.

What if your family can’t afford to purchase a battery and you like to camp off-grid where no electricity is available? Talk to your child’s sleep doctor or nurse practitioner to find out if it could be safe for your child to camp without using their sleep machine. Whatever you do, we hope you enjoy your summer as a family!

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Summer Break

Sleep is a huge part of being healthy and feeling well. Some kids and teens have a good sleep routine during school, including wearing their sleep mask, but then stay up too late playing video games or watching TV during summer vacation. This can lead to also getting out of the habit of wearing CPAP or BiPAP™. Not only does this make it harder to get back into those good habits when school starts, but there are health risks when kids don't use their therapy. So, it's important that kids don't take a "break" from taking care of their health on summer vacation. Parents can help their children to maintain healthy routines on summer vacation by setting a reasonable bedtime and reminding kids and teens to put on their sleep mask.



Don't take a break from your sleep mask on summer break!

Ask a Respiratory Therapist—What kind of mask is best for my child?

CPAP and BiPAP™ masks are definitely not one-size-fits-all, which is why there are so many different types on the market. If your child is struggling with their current mask, you might be wondering what kind of mask is best for your child?

To start with, let's consider some different categories of masks:

- ⇒ Nasal Masks—fit snugly around the nose and are the go-to type of mask for pediatric patients. There are several nasal masks that are designed specifically for kids.
- ⇒ Nasal Pillow/Nasal Cradle—fit either in the nose or under the nose. They typically have less material touching the face. These masks are only available in adult sizes, but they may fit some adolescents and teens.
- ⇒ Full Face Masks—cover both the nose and mouth. The traditional kind fit on top of the nose and the chin and some newer types fit under the nose and on the chin. This type of mask is typically used for patients that are not able to breathe through their nose during sleep. These masks also are mostly available in adult sizes.

So, what are some factors to think about when choosing a mask for a child or teen?

1. The first thing to think about is safety. If a child is not able to remove their mask by themselves due to their age or disabilities, a nasal mask may be the safest option. It's always best to check with your doctor, nurse practitioner, or a sleep lab respiratory therapist to make sure a full face mask is a safe option for your child.
2. The second thing to consider is mask size and fit, because a mask that fits well will be more comfortable and the therapy will work better. For small children, a nasal mask may be the only option because of what is available for their size.
3. Last, but not least, think about comfort. If your child's mask is very uncomfortable for them, they will be less likely to keep it on. For instance, if your child sleeps on their tummy, a mask that has a low profile will likely be more comfortable.

As you can see, there are a lot of factors to think about when choosing a mask. In fact, picking out a mask can be a lot like picking out a good pair of shoes. No shoes are comfortable for everyone and sometimes you find out that shoes seemed comfortable in the store don't work for you when you wear them at home. So, if your child's mask is not working well, please call one of our respiratory therapists and they would be happy to help you do a little mask shopping!

Mask Types



Nasal



Nasal Pillows



Full Face

Cleaning Corner—Water Chamber Cleaning and Replacement

Heated humidifiers make CPAP and BiPAP™ more comfortable, since without added humidity the air flow from these machines can dry out the nose and mouth. However, the water chamber (the refillable part of the humidifier) needs regular cleaning and maintenance to be used safely. Since the chamber is moist and warm, without regular cleaning harmful bacteria, viruses, or mold could grow. Here are some tips*:

1. Don't fill the chamber while it's in the machine to avoid damaging the machine with a spill.
2. Do use distilled water. Tap water and regular bottled water contain minerals that will build up on the water chamber.
3. Do empty it out and dry it with a clean cloth every morning after letting it cool down. Let air dry.
4. Do a weekly cleaning with warm water and a mild dishwashing detergent. Rinse well and dry.
5. Call your home care company to replace the water chamber every 6-12 months.

*These are general tips. Check your humidifier's manual for cleaning specific to your machine.



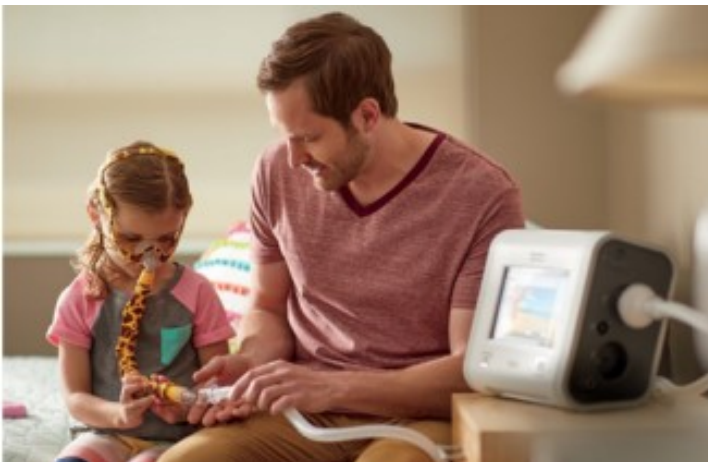
Parents Ponder—My child has neuromuscular disease and has been started on BiPAP™.

The unknown can cause a lot of anxiety, so starting a new therapy like BiPAP™ can bring new fears and worries. While each child is unique, it can reduce some of these fears to know generally what to expect after starting BiPAP™ as your child's disease progresses.

First, we would expect that your child will need higher BiPAP™ pressures over time. To find out if the current pressures are enough, regular overnight sleep studies will be needed. During these studies your child will wear their BiPAP™ and the technologist will adjust the settings, if needed.

Second, children with neuromuscular disease will often need the more advanced support of a home ventilator. Your doctor may recommend starting on a traditional BiPAP™ machine and then switching to a ventilator later when it is needed. Or your child may need a ventilator right away. Ventilators have the added features of advanced settings, as well as a built in battery back up. They can also provide some daytime support, which leads us to our third point.

“Our team is here to support and help you—you're not alone!”



Respironics Trilogy Evo Ventilator

Third, as their muscle strength weakens, some children with neuromuscular disease begin to need support with breathing during the day. Ventilators have a special mode called “Sip and Puff” (also called mouthpiece ventilation) for daytime use. Kids that use this can take a “sip” or breath anytime they feel they need it during the day.

If you have questions, concerns, or worries about your child's breathing therapy or diagnosis, please bring it up to your child's doctor, nurse practitioner, respiratory therapist, or nurse. Our team is here to support and help you—you're not alone!

Transition to Adult Healthcare



Transition is a process of moving from pediatric health care to adult health care. This transition often presents new challenges for families and youths with special needs or those using medical equipment like CPAP, BiPAP™, or a ventilator. Young adults need to learn, practice and become confident in the skills they need to manage their own health. Families need to learn about the adult services that will help support their teen in the adult world.

There are many resources available to assist families at chw.org/transition. Additionally, our team is here to assist you in this process. Please talk to us about any questions or concerns you have about transitioning to adult care.

Children's Wisconsin CPAP Program
9000 W. Wisconsin Ave.
Milwaukee, WI 53226

Sleep Lab: (414) 266-2790 #1
CPAP RT: (414) 266-4924
Pulmonary: (414) 266-6730
Central Scheduling: (414) 607-5280

Website: childrenswi.org/CPAP

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