



Complex Child E-Magazine

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Surviving Oxygen Therapy by Courey

If someone had told me a year ago that my son would be on oxygen full time, I wouldn't have thought I could handle it. There is definitely an adjustment period, but like all adjustments, it's temporary. Eventually you figure out what works for you and how to make life run as smooth as it did before.

Having your child on full-time oxygen can be rather overwhelming. The doctor or hospital sets up the basics for you and has supplies delivered to your house. Suddenly your house is full of tubing, tanks, and a somewhat noisy concentrator that is a constant reminder that your kid is not "normal."

When the respiratory therapist leaves after explaining it all to you, your brain feels so full that you sit there thinking, "I have no clue what I'm doing. How do I know that I'm doing it right?" There will be mistakes, but you are human and it's okay. You just need to learn to be forgiving of yourself. Eventually you WILL figure it all out. Just give yourself some time.

Some Basics

The first thing that you will be in charge of is figuring out what size oxygen tanks you need, how many of them you need, and what extra supplies (such as tubing and cannulas) are necessary. This may take a few weeks before you get the hang of it. Our respiratory therapist's rule of thumb is to always over-order versus under-order. Delivery guys are never thrilled with a midnight call. They are ALWAYS there if you need them for anything, so don't hesitate to ask if you do, but it is much easier on everyone if you just have more than you need.

When your child is at home, he will likely get his oxygen from an oxygen concentrator, an electrical appliance that generates oxygen. This plugs into a standard outlet and continuously generates oxygen. Unlike tanks, which need to be replaced or refilled constantly, a concentrator never runs out of oxygen as long as it has power.



Oxygen Concentrator

The different tanks that are used to go outside of the home are A, B, D, and E. A tanks are about the size of a one liter coke bottle but don't last long if your child is on a half liter or more. B tanks are about the size of a wine bottle and are really good for short trips. Some people prefer taking several B tanks with them instead of one larger tank.



A, B, D, and E Tanks

We mainly use the D tank when we go out. I prefer it because I don't have to worry about checking on how much is left and switching it out all the time. The E tank is what we use for long car trips, spare tanks in case the power goes out (concentrators are powered by electricity, so it is prudent to have at least one tank as a back up in case of a power outage), days when he's needing a lot more, or when he has to see a lot of doctors in one day. I can just stick it in the bottom of the stroller. The E tank does come with a dolly, but I find it is rather difficult to push a stroller or wheel chair and drag along a rather unwieldy tank and dolly.



E tank with dolly

We found a back pack at a military store that works really well with a D tank. That way I can strap it on my back with the feeding pump, and have both hands free.



D tank in a backpack

Figuring It All Out

One of the things that I worried about was whether or not being attached to yet another tube all the time was going to impact his physical development. Children are extremely adaptable, and that has really proven true with our son and his oxygen. We make sure to add about 47 feet of tubing on the concentrator so that he has free run of the living room and bedroom.

He does not get around well a lot of the time, and I was worried that oxygen would inhibit him more. If anything, it has given him the energy to do even more than before. After starting the oxygen, he actually started walking some!!! He went from being very lethargic and not even wanting to try standing or walking to actually being hyper sometimes! So the difference oxygen has made in his life is huge.

While I was worried that the tubes would limit him, he managed to figure it all out. If he crawls somewhere and gets the tubing hung, he yells "du du du du!!!!" (stuck) until I come and get him unstuck. He knows exactly what his limits are in regards to the tubing. There have been a few occasions when he has not been paying attention and has "clotheslined" himself on the cannula, but those times are few and far between. He also will yell "uh oh!" repeatedly if his cannula falls off.

To him, oxygen has just become a normal part of life. The oxygen makes him feel so much better that he gets upset if you try to take it off. It's just part of him, and he's fine with that. It's just a process of us parents becoming fine with it too!

The Tough Stuff

I have to say the hardest part of having a child on full-time oxygen was something I had never even considered before. It was other people. We were used to some questions since he has a feeding tube, leg braces, and just doesn't always look, move, or act quite like a normal baby. But in the last six months (since he went from night-time to full-time oxygen) pretty much every time that we have gone out we have gotten at least one comment.

That part is hard for me. It seems like since the oxygen is so visible and people are so caught up in the medical aspects of him that they fail to see he's still a super cute little guy under all the tubes and wires. All they see are the tubes.

The comments we get are often very intrusive. A lot of people say "oh, poor little baby!" and I just want them to see that he is NOT a poor little baby. He is happy and healthy in his own way, and such a joy. And there is always an awkward silence when someone decides to come up and ask "so, he's going to grow out of it, right?" I try to be polite and say "no, at this point none of his doctors believe he will ever be off it." Sometimes that awkward moment passes and other times it just gives the other person time to think up the only question worse than that: "so is he going to die?" Yes, he is going to die. So am

I and so are you. Stares and comments will become a part of your every day life too, and you just have to learn to let them roll off your back.

So now when I think about having an oxygen-dependent son, I don't think, "I'll never be able to handle it!" anymore. Instead, I think, "wow, living in a time when we can actually do something to help him is such a blessing." And really, the oxygen is a blessing. So give yourself some time to get used to it, and cut yourself some slack. Eventually, it will be so normal that you just do it all automatically.



Courey is mom to Linden, who has suspected mitochondrial disease and central hypoventilation causing chronic hypoxia.