

## **Tips for flying with a vent-dependent, very low-tone kiddo**

This is based on two plane trips with Lucas, a one-way, cross country trip when he was two and a half, the second a round-trip 3-hour flight. Flying was a scary venture for us – what happens if there’s an accident at 30,000 feet?!?! – but each successive flight got easier and easier. (If you can call our level of baggage needs “easy.”) So we thought we’d write up what we learned in the hopes that it will make flying easier for other families with kids on vents.

### ***Before hand***

1. Choosing an airline: It’s worth asking around to find out airline’s general reputation on supporting passengers with disabilities. We didn’t find any exhaustive lists, but we heard better things about the bigger airlines than the smaller, budget airlines. We flew Alaska both flights and had good experiences with them each time.
2. Talking to the airline: Most airlines have a special services desk – a designated number to call and talk to them about your specific needs related to disability. Each time we called that desk, they took notes about the conversation and what we were planning to bring so that when we arrived, the people checking us in would have all the necessary information about us. They also helped us check to make sure that our electronic equipment was cleared by the TSA for use during takeoff and landing. Most airlines also have a section of the website where they detail their special services for people with disabilities. For example, Alaska has [this page](#) and [this page](#).
3. Extra equipment: There is less oxygen up at high altitudes, so even though we almost never use oxygen, Lucas needed a low-flow (1.0 to 1.5 liters) while we were in the air. Our DME got us a portable oxygen concentrator (POC) which comes on wheels and is manufactured specifically for flying (like a mid-sized carry on suitcase). We had to take the wheels off to fit it under the seat in front of us, but that was relatively easy. We also carried a seat with us both times (see below).
4. Talking to the TSA: They have a new [“TSA Cares” program](#) that is supposed to facilitate travel for people with disabilities. They can get you permission for a family member or friend to go all the way to your gate – even on board – to help you load or unload. They can also help you ensure that all your gear is TSA approved.
5. Paperwork: Airlines and the TSA say they require paperwork for people to fly with medical equipment. (Though no one ever asked to check it at the airport.) We had a recent note from our doctor saying Lucas was cleared to fly, another from his pulmonologist with orders for the oxygen, and our one “one-pager” with general information about Lucas’s health.

## ***Planning Seating***

Seating was one of our biggest concerns because Lucas cannot sit up straight, and at this point all passengers have to sit in airline seats. There are campaigns to get wheelchair tie-downs on airplanes like on buses, but right now you have to get out of your chair at the door to the plane. They offer what they call “aisle wheelchairs,” which are airline-provided narrower wheelchairs to get you from the door to your seat, but this is not an option for Lucas. Fortunately he was still small enough we could pick him up and carry him.

Everyone has to sit up during take-off and landing. When Lucas was still using a car seat at 2 ½ years old, we brought his car seat on board. (Check that your car seat is TSA approved – not all are.) For our second flight, we took his tumbleform chair. Both of these worked well for him. (The tumbleform only worked, however, because the attendants on both flights disregarded TSA safety guidelines which say that the space in front of the seat has to be clear.)

Space is obviously key when traveling with all this equipment. Lucas doesn’t have the stamina to sit for hours on end, so part of what made these flights possible is the fact that he is still relatively small (so we can lie him down), and that we were able to get extra space. On our cross-country trip we flew first class, and for the second trip we bought an extra seat. We ended up using miles or paying ourselves for these upgrades. However, we have heard of families that have made the argument that these upgrades are medically necessary and talked the airlines into free upgrades.

## ***Packing***

Any extra baggage you carry that is medical equipment does not count as your carry-on baggage.

- Power/Batteries: We’ve heard that airlines require twice as much battery power (or even three times as much) as the length of the flight. The truth is that no one at the airlines would know how to check such a thing on our equipment, but it’s wise nonetheless to have quite a bit of extra
- What we took on board:
  - Ventilator
  - Suction Machine
  - Portable O2 Concentrator
  - Our regular travel bag that goes everywhere with us (with ambu bag, back-up trachs, etc.)
  - A carry-on suitcase with back-up everything: extra vent, extra suction machine, extra vent battery, extra p.o.c. battery, extra circuit, extra catheters, etc. It also carries the plugs for the vent and the suction machine that we use in the airport.
  - A backpack with toys, games, books

- A small cooler-pack with Lucas's homemade formula (you can take more than 3 ounces of breast milk or formula – even our weird-looking green homemade formula – on any flight)
  - Car seat or tumbleform chair
  - The kid!
- What we checked:
- One large suitcase that contained more medical supplies, the humidifier unit for the vent (packed well because these break easily in transit), and some clothes.
  - Another small suitcase with clothes, games, etc.

### ***The day of: checking-in and security and the airport***

It's good to have gone over the day-of plan, a bit like you'd write out a play, just to make sure all the pieces are in place and you'll have time for everything on the day of the flight. The second time was far less stressful than the first time for me, and I still was absolutely scared on my way to the airport the second time. What if we forgot something!! What if something fails!?!? The truth is that you can't prepare for everything, but a lot of preparation goes a long way to a smooth flight. The third leg (the trip home) was by far the easiest emotionally for me. I knew we could do it.

Our day-of-travel looked like this:

We had someone take us to the airport. Depending on how busy a travel time it is, we arrived 2.5 to 3 hours early. Just in case.

*Check-in* involved going to the check-in desk and presenting ourselves. All three times we flew, they didn't ask a lot of questions. We gave them our checked bags, they looked us up in the system (apparently reading over notes from our calls to them earlier, or maybe just looking up recipes for dinner – they definitely look at their computers for a while), and then told us to have a nice flight. Unloading from the van and checking in took about 20-30 minutes.

*Security.* The TSA has a new program called TSA Cares that is supposed to help people jump through the line. We hadn't called them ahead of time. Two of the three flights someone from the TSA helped us get to the front of the line quickly. On one leg they left us stuck in a long, long line. However, once we actually got past the person checking our documentation, the security scan itself took no more than 10 minutes. One of us went with the person inspecting. They took everything out of the bag with the extra medical equipment for inspection – one of us stood with that person. They then "swabbed" Lucas, his chair, and his vent. Once they sent his suction machine through the x-ray machine, and once they kept it on his chair and swabbed it too. One time they pulled out some mirrors to look under Lucas's chair. They looked at his green home-made formula and let it go through without any problems.

*Waiting* for the flight involved finding a place for Lucas to lie down and rest near outlets near our gate. We ended up having nearly an hour, which turned out to be fine – it gave us time to eat some food and rest before getting on the plane.

*Boarding* was fairly smooth – we were able to board first, rolling Lucas’s chair all the way to the door of the plane. We then picked him up and carried him down the aisle to his seat.

### ***On the plane and in conclusion***

Although Lucas doesn’t need oxygen usually, in the air he definitely needed it – we had the oxygen concentrator between 1.0 and 1.5L continuous flow throughout the flight. We felt extremely lucky that he did as well as he did on all the flights – his SATs stayed up, and we needed to do very minimal trach suctioning. We paid attention to his humidification, since his HME doesn’t do much to keep his airway humidified, and airplanes feel extra dry. On the plane we put saline drops down his trach a couple times, and that seemed to work.

At the end of each flight, we felt so relieved that it had gone as well as it had, we thought, “we could do this more often!” Of course the possibility is always there for a trach plug or some other medical issue you don’t want to be dealing with up in the sky, so the jury’s still out on our future travel plans.

The upshot of flying is that we left Minneapolis at 7pm and we arrived in Seattle at 8:30 pm, home by 10pm. As we thought about other families driving – taking 3-5 days to make a similar length journey, we felt lucky that the stars aligned for us and we were able to fly. We hope these experiences serve other families with trachs and vents who might be considering travel options!

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