

My POC experiences

In the fall of 2014, I needed a POC so I could be on oxygen 24/7. I researched POCs, I talked to DMEs, doctors, and respiratory therapists and they were evidently as confused as I was about POCs. It is embarrassing to admit that I thought I bought an Inogen One G3 with 5 settings producing 1,050 ml per minute (that POC didn't come out until late 2015). Instead, the one I bought had 4 settings and produced 840 ml per minute. If I had realized the one I was buying only produced 840 ml per minute I would have bought the Inogen One G2 which had 6 settings and produced 1260 ml per minute.

It was a costly mistake. My FEV1 dropped from 47% of expected to 30% of expected. It became hard to remain active and I tired easily. I was on the downward spiral of COPD and deconditioning. My quality of life was going downhill quickly.

I could not afford to buy another POC and had to wait until my SSDI kicked in at the start of 2018. I had a better understanding of POCs by then! I picked a DME that could get me an Eclipse 5 and produced almost 6LPM in pulse mode. Over twice as much as the Inogen produced. I soon realized it was too heavy even though I could play better tennis using it even though the Inogen was lighter.

About 3 months after I started using the Eclipse 5 I was driving by a different DME with a Respiration Ulta-Fill in their window. I stopped, looked, liked, and in short order I was using the Ultra-Fill. The Ultra-Fill would fill the four 3000 psi oxygen tanks provided to me every day. It gave me enough oxygen to stay active 2.5 to 4.5 hours per day using between 6 to 10 LPM. Those in the medical profession had always told me stay active but never helped me get the oxygen to do that. They supplied me enough oxygen to stay alive.

With more oxygen I was more active, healthier, and had a higher quality of life. I had asked about liquid oxygen many times, and every time told it wasn't available. In the summer of 2020 I bought a liquid oxygen reservoir and two portable units I could fill from the reservoir. I bought them cheap on eBay and found out I could fill my reservoir with liquid oxygen at the DME I was using and where I found the Ultra-Fill, but it was expensive. I had asked the DME about liquid oxygen before but they always replied, "not available." I had bought my own equipment and paid cash for liquid oxygen liquid oxygen, then it became available to me. Others could benefit by doing the same.

In the late spring of 2022 I found a reliable and affordable source of liquid oxygen and became a lot more active. I started losing weight, improved my mental and physical health. Liquid oxygen also improved my quality of life. In December of 2022 I was given another

PFT and my FEV1 was 45% of expected. If I had been able to get liquid oxygen back in the fall of 2014 I may have been able to keep working and not needed to apply and get SSDI.

In the winter of 2026 I decided to get a POC through the DME I am now using to use while driving and save the liquid oxygen for when I was active. My doctor wrote a prescription for the POC I specified. The DME supplied it. I had done my research on this POC and it should have easily supplied the oxygen I needed while driving, but it didn't. POC settings have no relationship to LPM and from my experience with this POC found that pulse sizes may be very misleading. I sent it back.

I asked my pulmonologist to send an order for a Rhythm P2-E7 and she did. They shipped me a Rhythm P2-E5. It was better than the last POC but barely provided the oxygen I need to drive. Sent it back. After talking to my local DME I asked my pulmonologist to send the order again, but this time to my DME instead of Synapse. Talked to them once two weeks later and haven't heard from them since then. Good thing I don't need the POC to go to the grocery store like some do!

How many hundreds of millions are paid out in healthcare costs because people aren't or can't get the POC or oxygen they need? A question I will ask legislators when I ask them to support the SOAR Act!

A lot of research needs to be done, not only to show congress what a reset of supplemental oxygen, and the DMEs could do. Studies would also be needed to prove more would benefit as I have. Medical professionals would also need to be reeducated to help us take advantage of a reset.