



## Making Educated Choices

Anna finds life giving breath with the Vivo 45LS

Meet Anna, mom to two daughters, grandmother to a sweet granddaughter, wife to Walter, and keeper of two dogs and a senior cat. In her mid-40s, Anna has Limb Girdle Muscular Dystrophy 2I (LGMD 2I), a type of neuromuscular disease (NMD) that can involve the respiratory system.

To support her weakened intercostal muscles and diaphragm, Anna has been using nighttime non-invasive ventilation for the past 12 years, working with Glen from Breathe 'n' Air Respiratory Services Inc. to ensure the proper titration. "Glen has been a godsend to me," said Anna. "It has been a very rough few years for my respiratory system as I age and my disease progresses."

*In her own words, Anna shared her story with Breas.*

About four years ago, I started to really struggle with shortness of breath and oxygen

dips during the day. Despite tweaking my settings on my nighttime ventilation, I continued to decline. It got to the point that I was struggling with dysphonia, laryngospasms, cricothyroid tension—all affecting my voice and ability to speak. I was experiencing many signs of CO<sub>2</sub> retention such as morning headaches, seized muscles, and out of character fatigue—to name a few. It became obvious that I needed some additional respiratory support, but what that support would look like wasn't so obvious.

I have a complex medical history, and with that comes complex needs and complex solutions. Within this time of struggle, I reached out to my respirologist, respiratory therapist, a US based not-for-profit named Breathe with M.D. Ltd, and my fellow NMD peers to seek advice and support. I was, at that time, on bipap only, but this became inadequate to support my increased needs. I was faced with a variety of choices to help my respiratory decline. The least invasive

of my available options was to try daytime ventilation. In fact, my current respirologist said without it, I would die within two years. With that knowledge, I learned everything I could about this delivery method and its suitability. This method delivers me the breathing power I need without yet needing a mask interface, and it does not involve the need for surgery. This seemed like a great, logical fit—with the added bonus that it is easily transportable.

The director of Breathe with MD Inc. sent me to Breas' webpage and Youtube channel where there were so many AMAZING and user-friendly informational videos and articles. My RT, Glen, also sent me a medical journal article from 'Respiratory Medicine', about the benefits of mouthpiece ventilation entitled: "Mouthpiece Ventilation in neuromuscular disorders: Narrative review of technical issues important for clinical success." So between all these various networks I was really well informed and set up for success with this next chapter of my life. It made compliance easy.

## Choosing and learning

I chose the Breas Vivo 45LS as my machine for a number of reasons. A large number of my NMD peers praised the Vivo 45 LS for being a compatible and comparable machine to the one they were used to for so long. They reported an ease in the transition from one machine to the Vivo 45LS; whereas many who used another machine which used the IVAPS software in their transition were facing so many frustrations—from stunted

and unnatural breathing patterns, to nuisance alarms, to sore muscles, to machines that were complex to understand and use, and which were bulky, heavy and hard to transport. As a bipap AVAPS user at the time, Breas stood out as a natural and glaringly obvious choice and I have never looked back!

I cannot say enough good about this machine and brand. The Vivo 45LS is small, compact and powerful. It is intuitive and user friendly. Breas' information through various media modalities makes it extremely user friendly. Breas painstakingly explains something complex and makes it easy to understand through their tutorials. Breas even has "suggested settings" and explained parameters to help alleviate the guess work.

My wonderful (and oh so patient) RT came down and spent the entire afternoon with me to make sure everything was just right and to make sure I understood everything I would need—how the machine worked, how the settings worked, etc. It doesn't get more supportive than that!

Thanks to all the great info and direction from both my RT and Breas, I was easily able to dial in settings that worked and supported my needs with very little interruption or fuss.

## The difference

With the addition of volume support mouthpiece ventilation via the Vivo 45LS, I have ceased having to deal with slurred speech and daytime headaches. My thinking is much clearer. I feel a lot more present. To me, the most astonishing aspect of

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need because of my Vivo's light weight and compact portability, makes things infinitely easier. Previously, with my bipap, I'd have to spend energy I didn't have to lay down in bed tied to my machine—all of which required the help of my caregiver. But now I can get breath, and support my breathing muscles, on the go and most importantly, independently! In a world where I need help with almost everything, this "small" bit of independence is not small at all—rather it is absolutely monumental.

incorporating mouthpiece ventilation is that I can once again socialize and join in on conversation with my family and friends because the power behind my voice has returned. I do not have to use my auxiliary muscles nearly as much since using MPV, so my vocal cords and cricothyroid muscles are not seizing and spasming as they once were. I once again have range in voice—something that I thought was gone forever! I no longer need to sit quietly during the day in order to nurse a headache, nor am I randomly falling asleep anymore. My many oxygen dips and blue lips have dissipated completely.

The quality of life I regained is huge! I used to get very short of breath, and then panic about it because I'd be out away from home where my bipap was located, but now I have deep fulfilling breathes available wherever and whenever I need it. That is life-giving, literally. It means I can re-engage in parts of life that previously I had to limit or stop altogether.

Having breath, whenever and wherever I

Currently, I use my Vivo 45LS for daytime mouthpiece ventilation only because I wanted to give myself time to adjust to this new way of life. I will eventually be using it for my nighttime ventilation as well, and I know when that time comes, I'll be in good hands and my respiratory needs will be met.

Using mouthpiece ventilation has changed my life and the positive impacts cannot be overstated. I readily and enthusiastically commend mouthpiece ventilation, and specifically the Breas Vivo 45LS, to any NMD patient. I hope pulmonary and respiratory clinicians come to know the life-giving power of this machine for their patients who use personal ventilation, whether it be daytime and or nighttime or invasive or non-invasive—there are settings for everyone's needs.

Anna, we're so honored to be a partner on your medical journey. Thank you for trusting us to support your ventilator needs, and for sharing your experience with us.