

David

Breathing and ventilation

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Did breathing tests, which is like an asthma, it's like very similar to an asthma review when you have to blow down a tube and keep blowing. And then I had another one on the second appointment at neurology, but I'd already flagged up with the NOTS team [Neuro Outreach Team Sheffield] that me breathing weren't very good.

I was becoming short of breath. And I also noticed when I laid flat, I were very out of breath and not like doing it through educational purposes.

You're, when you've got MND, you tend to do a bit of research yourself and that MND can weaken your diaphragm and that was the case. So then on second breathing test, it showed my breathing capacity had gone down to 69% and that triggered them to say well, you need an NIV breathing machine and we'll get you an appointment. They'll show you how to use it and when to use it.

And yeah, and I now, I've got the NIV and I use it every night and it works a treat. I don't get no bad nightmares anymore. And I don't wake up with an headache. But me breathing, it has helped a lot. And that that were nightmares and the waking up, with an headache.

One of the nurses said that at the Hallamshire. They said, do you wake up with an headache every morning and have nightmares? And I'm like, yeah, yeah, I do yeah. And it were that were another trigger point to say that you're not getting enough oxygen into your bloodstream, which is triggering headaches and having bad nightmares.

So yeah, it were like, as soon as I said this were happening, they like just, it just like triggered that chain reaction of getting the help and getting that support to get the NIV what I needed.

And the support were put in place and it kind of got like they knew. Did blood oxygen where they take a sample of blood and it would pretty much like from me walking out that appointment with neurology, they said next step were to see a specialist at Northern General for the NIV for breathing equipment, what you're going to need.

I find it OK. It's just hard to put on with the weakness in me arms and me upper body, because it's like a face mask, what you have to wear over your nose and your mouth and it straps around your head. So I've had to figure a way out how to get it on with lack of strength. But that's going to get, again, that's linked to the PA, personal assistant, going to be coming and helping me.

But yeah, the NIV itself has helped a hell of a lot. If I get short of breath during day, I can wear it and I do tend to wear it more at night, which it helps a lot. The specialist did say the importance of using it at night and that it's going to like it puts more air into me lungs and it's basically if I don't use it, it'll shorten my life. And that were like cut, like cutting a long story short on it. And it were very important to use it.

I think sometimes you need to hear that. You need to hear that the reality that situation of like, why you need this machine. And yeah, I mean, he were a lovely chap, but very straight to the point, which I respect that a lot if someone's straight to the point about something.