

Meena **Breathing and ventilation**

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Papworth Trust do that, I think. Since diagnosis he's been having I think it's every three months. He was doing really well at it. So they increased it to six months and then they did a sleep test. I think they test breathing while you're sleeping. And they had this machine that was attached to his finger, which dad found absolutely freaky, and of course he stuck in his bed like a log, wouldn't move because he thought if he moves, this thing would really read incorrectly.

So he messed up the first test because it was just so rigid, it didn't really record it properly. So the second time we had it and I said to him, you just need to relax, just forget it's there and just, you know, do your thing. So I think that was a better test result.

So thankfully, I'm pleased to say he did it correctly and he passed with flying colours, and doesn't actually now need to go to Papworth again for these lung tests for a year. So that's amazing for him. That's really boosted his confidence too.

When initially they were concerned about his breathing because dad did it wrong, they did suggest that he would perhaps have to have an oxygen machine next to the bed, which needs to be monitored. And I think the lady was so concerned, she was kind of saying to me, you need to be sleeping in the same room while we have this machine.

And, and I was kind of like freaking out because I know for my dad, this is not the information he needs because he'll just freak out even more. But luckily, yes, so we're aware that, that at some stage potentially if his lungs do take a turn for the worse, then a ventilation machine is there to help him breathe.

But again, aids are a good thing and that's kind of how we want to see it. But luckily Dad doesn't need that at all at the moment, so he's fine.