

## **Geeta and Sheena Breathing and ventilation**

### **Sheena**

So, my mum actually attended a respiratory appointment with one of my siblings, and it was suggested that mum was given an NIV and it was suggested that she uses it at night time.

My sibling and my mum sort of got a little bit confused with the information that was given, and when they came home they were a bit scared. And the message I think the only message they'd caught on to or brought home was that if I start using it, I'm going to need it all the time.

So we refrained from using it. So we had this piece of equipment that we didn't use, but we carried around with us all the time because we didn't really know what it was for, why we had it.

But we were just still carrying it around. So we went, we went on holiday and we took it with us. And then I don't even know how to set it up myself, but again, it was after hospital admission for a chest infection that they'd said, actually, mum needs a little bit of support with her breathing. And then we started using NIV.

It's continuous now, but it wasn't previously.

### **Geeta**

So it wasn't before.

### **Sheena**

It was just night time. Yeah. And mum reported actually when she first started using it that she'd had a better nights sleep. She was more refreshed the next day, more awake, more energy. And I don't know,

I was a bit annoyed that mum was using it at the start because I didn't understand the importance of it. Or why? Because I was like, I don't want her to use a piece of equipment that she's kind of become reliant on because she's not going to use her own functions.

But it was after time that I realised that actually it just supported mum, where she's not getting that full sort of benefit of breathing with her own sort of respiratory system.

And then again, after another hospital admission for her chest infection, it had transitioned to more frequent day use. And now it's continuous. Yeah, we've adapted to it. We take it everywhere with us.

**Geeta**

I couldn't stand it, because it was like it's because it's a bit uncomfortable, but now I'm used to it.

**Sheena**

When – sorry. When mum did first get the NIV and we were using it in the day. I feel like mum was a little bit ashamed to go outside with her NIPPY (Non-invasive positive pressure ventilation) because people would look and stare.

And I understand why, because it's something different. She has a mask on her face, and we realised that she's a bit more reluctant to go out.

So we did say to mum because mum was very much interested in helping other people and research. We said, you need to think of it as research. So when you're going out, you're acclimatising people that will look once at you.

But if tomorrow they see somebody else, they're not going to stare at that person and maybe it will help that person how they're feeling. They'll just get used to it.

And then when we explained it to mum in that way, mum was happier to go out. And a few people have approached us in supermarkets and asked us directly, what is that machine? Why do you have it?

We don't mind and it's good to educate people and people will stare. And we'd say someone we would look at somebody if they had it – discreetly. Because you're interested. We're all curious, but it's good to expose people to these kinds of equipment, so it's not such a big, strange...

**Geeta**

Because sometimes, there are little kids who get scared. If there are little kids who see me. They don't come near, because they don't know what this (NIV) is.

**Sheena**

A couple of family members have brought their small children, and they've been scared to go near mum because of the sound of the machine and just the appearance.

But after a little bit of explanation and again they've become acclimatised to it. We tell them that mum's a robot, we just make it fun for them. So now they're really enjoy going to explore mum's NIPPY and like I already explained my niece, she pulls it off and tries to have a go of it as well.

So yeah, it just shows you that you can get used to it, that they're not scared anymore. They will go, yeah. Even with the cough assist, they will just sit quietly and just continue as normal.

Whereas it probably was a bit traumatic the first couple of times that they did see it.

**Geeta**

The only problem with this is my eyes can water a lot.

**Sheena**

Yeah, because of the cold air that blows into her eyes. And mum struggles a little bit because she has hearing aids as well, the ones that go around the back of the ear. So she's been unable to wear them because the sound's really loud with her NIPPY.

**Geeta**

So I don't wear them anymore.

**Sheena**

So mum has selective hearing now. You hear what you want to hear? Yeah.

**Geeta**

I have to ask her. Two, three times. Because what they're saying. I can't understand.

**Sheena**

Also because the machine's is quite loud at the start, we didn't realise that mum couldn't hear us as much, so she would get angry at us and say, what are you gossiping about?

What are you talking about? Like, we're not talking about anything!

**Geeta**

It was, I would say. Why are you, mumble-

**Sheena**

Why are you mumbling.

**Geeta**

This is because mumbling- for me it would be like they were mumbling.

**Sheena**

You've got good at lip reading now though. Yeah, yeah. Mum likes to be part of the gossip, so she felt like she was missing out.

So mum's actually had a few different types of day masks. Mum's got quite a small face and frame, so some of them weren't really suitable for mum. I think we tried one that was just around the nostrils in hospital that wasn't-

**Geeta**

They were not comfy.

**Sheena**

So it was just trial and error. So the night mask and the day mask, we've now got the right combination of the day and night mask that's comfortable for mum and works the best. So there's yeah they look very different as well as some of the day masks.

If mum ever visits A&E at a different hospital the next day, early morning, they will somehow know they must get a notification on their system. That mum's been in. They'll ring us and ask us if everything's okay or if it is something to do with mum's respiratory system or a possible infection.

They're in touch with us straight away. Or if mum's admitted, they're usually one of the first people to come and visit me on the ward.

**Geeta**

Yeah come and visit.

**Sheena**

They'll check her stats the readings on her machines and just see how mum is and if we've had any broken equipment or any issues, they're always at hand.

We do have an out of hours number. The only thing is obviously on the weekend and out of hours, we worry a little bit that sometimes we can't obtain that equipment, but usually by Monday it's already ready.

**Geeta**

Call the...Dial the weekend number, emergency.

**Sheena**

Emergency one.

**Geeta**

Yeah because last time the mask broke it was a Friday.

**Sheena**

Yeah yeah. So we've got a weekend number now.

Also my sister got married earlier this year. So we needed extra batteries for mum's mobile NIPPY as well. And there were really good at loaning us multiple batteries so we could have the mobile one running throughout the whole day and have enough supplies and have supplied us with extra.

So when we do go out and about, we've always just got a backup. Just in case. We do carry the mains one with us as well, just in case. But we've also got some batteries, which is reassuring for us now that mum's on it almost continuously.

So we know that we've got something with us just in case.