

Tracy and Iain Communicating

Tracy

The SALT team [speech and language therapy] came to talk to me about banking my voice very early on and I had to read Alice in Wonderland. They explained why I needed to bank it, so I agreed to do it.

Iain

Yeah, I would agree. I would stress that bank your voice before it changes because in Tracy's case it changed so quick. So we was really lucky. The speech and language team come and said get it banked.

Tracy

MND has meant I lost my voice very quickly and I have to use my eye gaze to communicate. Having been a very sociable person and being a languages teacher, I have struggled with not being able to talk and for me it is the worst thing.

It is a lifesaver because it's my only means of communication, but it can be frustrating when it doesn't work and I want to throw it out of the window.

Iain

Yeah, which is well, not, I won't say quite often. It doesn't. It's very, very good. I don't know how on earth people used to manage before this. We wouldn't be without it. Because for me, losing her voice is the worst. Of all the problems, the voice going is by far the worst.

And she's such a prolific user. She does everything on this, everything she's got. So she's got Netflix on it, Vinted on it, a phone on it, all the TV stations, turns lamps on and off with it. She can put her chair up and down with it. It's an amazing thing.

Well, it's been life changing for her, and for me, because without it, she won't be able to communicate with me – she can't talk to me, she can't tell me what she wants, she can't tell me if she's in pain, she can't tell me what she needs me to get for her.

With it, it means that I can leave and leave her alone for short periods because she can call me on it, she can page me on it, she can text me on it, email me on it, send me shopping lists on it, which she does a lot. Yeah, we'd be – without it, I don't know you'd cope without it now.

Tracy

It's important to me to have my own voice on the eye gaze because I don't want to sound like a robot or lose my individuality.

Iain

I was quite emotional when we first heard the voice because we hadn't heard her voice for so long, maybe six weeks. But it was like, wow, that's, you know, I mean, it's not an exact likeness, but it's very, very good. Like crikey. It's yeah, very clever.

It's just we're trying to find some more voice recording because you really need half an hour. What they have done within a minute so far, it's just not quite right. It makes her sound very posh, like a posh telephone voice. I'm not saying she's not posh, but yeah, so it's almost there. But hopefully we can get some more voice from the previous job and should hopefully be able to get it spot on. So I look forward to it.

Tracy

In social settings, I find it hard to keep up with conversations, but friends and family have learnt to be patient with me. I don't always like taking it out because people stare at it, but I am getting better with that.

Iain

I think the problem is when you're in groups of people, the conversation moves on so fast. As I'm sat here watching what Tracy's typing and then the conversation's moved on. So sometimes I say, well, just slow down a bit, you know, Tracy's got an answer to that. Or, she'll type it and then she'll delete it. And I'll say just don't delete it. You know, you've got something to say, just say it.

But people are getting used to it now. This particularly eye gaze is really good though, because there's a screen on the back as well. So it comes up on the back. So if we're in somewhere that's quite noisy and I'm sat opposite rather than sat next to her, I can just, you know. Sometimes even if you can't get it loud enough, she'll just type it and I can read it or she doesn't want it to be played loud so people don't hear it. It's getting better though.