

MND Matters: Episode 4: Voice banking

Intro: You're listening to MND Matters, a podcast from the MND Association.

Steph: Welcome to MND Matters, brought to you by the MND Association, alongside members of the MND community, including people affected by the disease, health and social care professionals, and supporters, we will be bringing you stories, information and expertise direct to your ears. Subscribe to ensure you don't miss an episode. I'm Steph Steward and I work in the fundraising team.

Nick: I'm Nick Cole and I work in the research team.

Steph: And we're delighted to welcome two fabulous guests today. We're joined by Sue Lodge and she lives in Wakefield with her husband Steven and was diagnosed with MND in May 2012. She's going to talk to us a bit more about voice banking, and she is also joined by Richard Cave who is the MND Association's speech and language therapist. He has worked closely with Sue to support her voice banking. Thank you both for joining us.

Nick: Richard, our voices are very much something we take for granted and I think only when we think about potentially losing our voices do we kind of consider how important and how personal it is to us in terms of many different factors; sense of humour, communication of course in many different ways. Can you just explain to us from your perspective what a voice of a person means to them.

Richard: Well our voice is, is really closely linked to our identity and to who we would like to, what we would like to represent to everybody else and so it communicates so much more than just the words. It communicates how we're feeling and, as you say, the humour. It, it conveys our geographical, social and educational background. All in addition to the words in which we are saying so, you know, our language is such a powerful thing that the way we sound with our voice conveys a lot of the message without the words. Indeed, you know, we can say very little and actually convey a lot just by the way we sound.

Nick: And in motor neurone disease we know that a proportion of people will lose their voices sadly. Erm, what percentage of people will lose their voice eventually?

Richard: It's going to be around 80-95% of people living with motor neurone disease that are going to lose the power of their speech for everyday conversation and, erm, as a speech and language therapist, you know, we work with people who are losing their voice, who are in the process of losing their voice, to find alternatives using communication devices or some alternative. The most important thing for us working with people living with motor neurone disease is they get to carry on communicating what they want to say, when they want to say it and who they want to say it with, so that is the biggest priority. But it is, unfortunately, it is the case that for everyday speech a very significant amount of people living with MND will kind of lose their voice for everyday communication.

Nick: Thank you.

Steph: And Sue, Sue you were diagnosed in 2012. How has MND affected your voice up until this point?

Sue: It's affected my voice quite a lot actually. My nephew's wife last year at some point saw a video of me years ago and she actually commented about how broad Yorkshire I spoke and how much my

voice has changed, so it has changed quite a lot. Obviously your voice becomes much slower. People at the moment still seem to be able to understand what I'm saying. On the phone, people do ask me to repeat things sometimes but I'm, I'm quite lucky with the form of MND that I've got. I've got PLS not ALS so my progression has been slower thankfully but then it, it is changing and if I'm ill my voice tends to go completely which is frightening. If you think your voice is going to go overnight which it has done in the past when I've been ill, before I banked my voice, I was just in panic because I was thinking is it going to come back? Isn't it? Is this the point where my voice goes forever? I was, I'm hoping still that as my MND progresses, my voice progresses at the same rate, hopefully, but you never know with MND. It can just go.

Steph: Absolutely. And why was it so important to you to bank your voice so you know you've got it there.

Sue: Well, as Richard said, to me my voice is my identity. When I'm on the phone with people, they know it's me. My Yorkshire accent is something that I'm proud of. Apparently, I'm less Yorkshire now than I was when my voice was normal, we'll say. But it's me. It's who I am. Friends know it's me. Family know it's me. But it is your identity and when you're living life normally, nobody thinks about their voice, but when you have a degenerative disease and you know you're going to lose your voice it becomes even more important that you bank it because eventually MND will take every part of me but I know now it can't take my voice. I've got that tucked away that MND can't reach. It's getting everything else but it won't get my voice and that is why it's important.

Certain phrases that you say to family members, I have a niece and when she comes in we'll say 'oh, hello, baby girl'. Now, if I type that into some generic machine, yes it's being said but it's not me. It's not me saying it to her which is important. People all take that for granted because you can speak normal, saying everyday things. Just like saying I love you to your partner. If a machine says it for you, it's not the same thing. Though eventually a machine will speak for me, it's still me saying to my husband I love you. It's not some horrible generic machine saying it for me.

Richard: That's so lovely Sue and thank you. Thank you for saying that. And I can hear, I can hear your Yorkshire accent loud and clear. I can, I can and it's lovely. You know, you talk about, you talk about so many things there and actually how we speak affects the kind of, there's a sense of self so clearly linked to how we speak and how people, how we think others perceive us and I work with many people living with MND who just want to keep working, who want to keep going out and keep doing their things and meeting with their friends and actually, erm, the worry is that, you know, as their voice change people think they're different. I want everybody to keep all their friends, to keep everything that they do, go out, do the things that they want to do for as long as possible. With MND, you know, sadly the evidence is that our social networks, our groups of friends, our going out, our doing things, it just, it just falls away a lot more and part of that is because people think, ooh, my voice is changing, people might think I'm a burden or I'm just different whereas inside I'm actually the same person. I'm still the same person but there's this worry about being a burden, so, and I also loved what you said Sue about those important phrases in life like 'I love you' and when I work with people who bank their voice every single day and it's that phrase that comes up all the time. To my loved ones, I want to say 'I love you' and I don't want it, the box to say it on my behalf. I want to say it. So, it's just so powerful and so thank you Sue. You continue to inspire me, so thank you.

Sue: Thank you. I know it is just silly little sayings like, excuse me, one of my sayings that I have recorded is 'make us a cuppa tea, Dodgy'. Now, that's my husband's nickname 'Dodgy', and if I was to type in 'make me a cup of tea, Dodgy', it wouldn't say 'make us a cuppa tea, Dodgy' which is Yorkshire. So there are your own dialect you lose when someone else, something else, say a machine, is speaking for you. Like when my great-nephews come, one of them's autistic and we say,

from when he were born, I called him 'little one' and when I see him I go 'oh, hello little one'. So, I'm not, whilst I don't want it for me, it's important I keep my identity. I do understand for some people it's too late for them to voice bank and so they have to use that but, for me, I don't want it. I need my family to know it's me and for my own peace of mind as well, I wanted it banking.

Nick: Yeah. Very important to maintain that aspect of your personality and those little phrases. You've taken part in voice banking so you could tell us a little bit about what that process was and also have you started to use the voice already? I'm sure you must get tired at certain times of the day, that kind of thing, so you're at that sort of transition phase I guess where you are starting to use it to some extent?

Sue: Yes. I'm going to be honest. I found the process at the beginning very hard. At my local hospital I first saw two ladies, older ladies, well I say older, they'll be like me in their fifties. I never thought I'd describe myself as old.

Steph: You're not old Sue, you're not old.

Sue: And when I saw them in the speech and language clinic, I did ask about voice banking and they both actually said 'you do know that you sound like a robot and your voice is too far gone to bank'. And I went 'but people still understand me' and they said 'yes, but your voice has to be of a certain level to do it' so I thought, I thought no, I'm not having that thank you very much. So, when I came out of the clinic, I did some research and found Richard Cave's number and contacted Richard and explained what had happened and that I was told I was too far gone, my voice was like a robot and the machinery, the recording wouldn't be able to pick up what I was saying. And Richard said 'no. I will help you. This is ridiculous. Everybody should be given the chance to bank their voice'. And so I received a machine from the MND Association and a young man called Teng, he came every weekend and helped me.

When I did the voice banking, I did 1600 phrases because I also did my own phrases as I've said and that's how come I got my voice banked. And then I was put in contact with a different speech and language therapist called Roxanne at my local hospital and she helped me with Richard and my voice, but I just couldn't believe the stress I had to go through and the shock of being told by two speech and language therapists that were supposed to be there to help that I was beyond help and just go away and we'll get you an Ipad when you need it.

Nick: That sounds absolutely awful. I guess one of the great things about you coming on here and spreading the word about voice banking along with Richard is that, you know, we can, we can get that message through to people that, you know, don't wait and it is available and there is some incredible technology now, that we can really use the voice that you have while you have it to do this. Were you able to record in your own home? Is that what you did?

Sue: I did, yes. The MND Association gave me a laptop and a headset and Teng, the young man, came, set up all the programme for me. I went through different things on my own, sat at 10-15 minute intervals doing it and it took me months but the young man was always on the end of the phone. He helped me and then, in the end once it was all banked on the MND machine, Teng came yet again and he then sent it to America. It was then all sent back for me to, well, me and my family. Teng suggested that we all get together and listen to my voice as it came back because you can actually, I don't know how but it's manipulated, but there's three different sets sent back and you choose the one that you think is nearest to you. And so my family helped, listened to everything and we chose the one that was nearest to me. But it is me. And you definitely tell it's me and I have on occasions used it since it's been finished. As I've said when I've been ill I tend to use it then. If I get a

cold or chest infection I use it then because my voice does literally go overnight if I'm ill sometimes, depending on how bad the chest infection is or sinus infection, so I do use it.

Nick: Yeah, thank you. Well, your voice sounds good and I hope that you, well I'm very glad that you're pleased with the voice that you received.

Sue: I am

Nick: Richard, is this, would you like to just tell us about the process now. About how it's changed and you know, how good does a person's voice need to be to be able to bank their voice?

Richard: Well, this is, you know, this is a really interesting question and Sue thank you for sharing, thank you for sharing that. And we have talked about this before I know. I think there are a couple of things to say is how good does the voice need to be? Well, actually, it, the choice of whether to voice bank or not is not the speech therapists. The choice of whether to voice bank or not is always the person living with MND. It's always their choice. What we do as speech and language therapists is, we can advise. We can say, well this is what we think and there are lots of different options available now and in my view, if somebody wants to bank their voice then they can just go and bank their voice and that's absolutely fine and there's no problem. And, you know, people often ask me, professionals say, you know, well, you know, how bad or how dysarthrical, how slurred does the voice have to be, you know, for voice banking not to be an option? And actually, the answer is that in from what I've seen having worked with many, many hundreds of people with very kind of various levels of voice change, that I cannot predict who will like the outcome based on the voice quality because some, because some people who, whose voice is absolutely unaffected at all bank their voice and it comes back and they say Richard, I don't really like that and that's absolutely fine. That's absolutely fine because it's their choice. And other people who, whose voice has changed very significantly bank their voice and actually they're really happy with it so there's no, there's no relation between kind of voice quality and voice banking's satisfaction and use from what I can see.

Back in 2018 when we kind of worked with a lot of volunteers on the voice banking volunteer programme, we helped around about 100 people to bank their voice and the average time to take, the average time for them to get through that process was 3 months. Now, fast forward to 2021, and, most of the people who are banking their voice today only need to record 50 phrases and that is done usually in a single session. More and more people are doing it now. In fact, almost everybody, because it's so easy and, with the speech and language therapists now, it's formally being kind of put into their role that they will help, that they can help and they will help people to voice bank. And so, everything is slowly coming into place since, you know, kind of over the last couple of years I have trained, on behalf of the MND Association, more than a thousand speech and language therapists on voice banking. More than a thousand, because what I want to do is have a good chat about this stuff with them and, at the same time, I'd like them to bank their own voice. Just go through the process so that they know what they're asking people to do and also they have, they can speak with knowledge as to what we're talking about here. It's not kind of an abstract term. They've been through it, they got the emotional scars, they have earned that and now, you know, and what's better than that, the very next person they see who's living with MND or indeed any other diagnosis that may, that they may come across, that may help, that voice banking may help, they can do two things. They can talk about voice banking and they can show voice banking.

Sometimes it feels when I've worked with people who voice banked, sometimes it feels, it doesn't feel like it's so important for them. It feels a lot more important for the families, for the families around them. It's about communication and, you know, it's a two way process and actually having

the people that really kind of matter in their lives to have their say, I think, I think is really helpful too.

Nick: What are the barriers to people doing it and, in terms of cost and the things we provide, if people want to do voice banking, is it a prohibitive cost or how does it work?

Richard: So, to answer the last question first, everything we talked about here today is free for people living with MND. Everything. So, we will, we will loan equipment if they need it we can loan laptops, we can loan headsets. From a barrier perspective, you know, anyone listening to this, don't worry about cost or equipment, you know, that can, that can be sorted out. And, you know, what are the barriers? The number one barrier is letting people know about this stuff and letting them make their own call on it at a time that, where they feel comfortable and, you know, things have changed with all the training and stuff. And I sit, I often sit with the team at Kings College Hospital Motor Nerve Clinic and they are brilliant because they talk about voice banking, you know, very, very soon after diagnosis, erm, you know, within a week or two if that's what people would like to do. It's, it's a sensitive topic. It is, because, you know, kind of the diagnosis is a very difficult time and people get a lot of information very quickly but, you know, the one thing I found that, you know, if I'm invited to talk to people who have recently diagnosed with MND, just to share with them the information and, you know, it's up to them. If they want to talk about it, that's fine. If they don't, that's fine but they know who to, who to speak to if ever they want to talk about it in the future.

And, you know, voice banking is not a declaration. We're not, no-one is saying anybody is going to lose their voice because of voice banking. Not at all. What we're saying is this is an option for you and we can spend an hour or two banking your voice and then you don't need to think about it again. And, if you want to use it, that's fine. Later, if you don't, that's absolutely fine. You're in control. And there's one more thing here that, you know, these days the technology is getting better and better. Not perfect, but it's getting better, so we have, we work with different voice banking providers now. Some are, you know, we can do it in 50 phrases. Others, a few more phrases but they offer something called voice repair and this is for people whose voice has already changed and it feels like it's significant and what that service does is they blend a person's voice with other voices from the same region, in Yorkshire perhaps, and, you know, the same region, and they kind of build this kind of hybrid, this hybrid voice which has, which is clearer but also retains a sense of the person recording. If you want to do it, let's do it. Let's do it today.

Nick. Yeah. I think, I think you raised some very important points there and we've also really emphasised, you know, Sue wants to keep her own voice but I think it's important that we also say that, you know, if you haven't banked yet or if you are unable to do it with your own voice, you know, there are many things available and real positives to having a voice. And, you know, can you just touch on Richard, you know, about the opportunities for people who haven't banked and maybe feel like they can't but actually they really can have a voice.

Richard: Of course. And actually, yes, there's always a discussion to be had because many times people, you know, kind of close to the person with MND have volunteered to bank their voice so that the person living with MND could use it. A couple of months, a few months ago, twins, the twin of the person living with MND banked his voice on behalf of his brother and also we have sisters and a father and son and, you know, it, it feels like it's a very positive, it feels like, at least I hear, it's a very positive act that, you know, kind of, say, the son and the father, the son says, you know, I want to do something for my dad. I feel helpless but I can do this. For people who have recordings like YouTube recordings or something like that, the technology has moved on that some of those can be used as well and a few weeks ago I worked with a man who had some YouTube recordings, it was only about 15 minutes. He was being interviewed in his garage talking about his motorbike and

every so often the motorbike would be revved up and it was all, it was all echoey. I mean, it was not you know, it was not Abbey Road. That was, that was what I was trying to say. And actually, Speak Unique, other voice banking services are available, but they took that recording and created a voice bank in which the family really liked. So, there are lots and lots of options.

Steph: Sue, you mentioned that you've got your voice banked on your iPad and on your phone and how does it feel, like what difference does it make to have it on both of those devices and, I know you've started to use it at different times during the day, maybe when you're more tired or depending on the circumstance you're in but, you know, is that quite easy for you to access? What difference does it make to have it right there and then and what sort of times and places are you using it at the moment?

Sue: I feel I need it on both devices. My iPad is fine for when I'm in the house and you can hear now me voice is getting tired, so I use that in the house and my mobile if I have to, when I'm out I use my mobile. That is why I wanted it on both devices so that I wasn't having to carry a big heavy iPad because part of MND is your muscles weaken and so, for me, holding an iPad out, while I'm out and about can be quite heavy so I've found that my mobile suited me better for when I'm out and about. And so it's just ease, ease of use for me. I know some people may just decide to keep it on an iPad and take it everywhere, but I just find that for when I'm out and about the mobile is better for me.

And when we're on about people not recognising your voice and asking you to repeat a while back, I'm quite lucky. I like to go in my local Marks & Spencer's, and one of the girls there two years ago did quite a big fundraising drive because her sister got it and so in my local M&S they are fully aware of MND. So, when I've been and if they've said 'sorry, can you repeat that', I've repeated it and then said, oh, I've got MND. That's why I'm a bit slow speaking and they've gone 'oh, don't worry. We know all about MND. So and so's sister had it'.

Steph: That sounds great Sue. I'm glad you've got them as well to use especially if you're out and I know you said sometimes on the phone. I mean your voice is very clear. I can understand you. I know you say you're getting tired but, you know, we can still understand you clearly but, erm, it's that thing where, I guess if you're on the phone sometimes and you're tired, it's good for you to have the device to be able to do that, that repeat from your banked voice and it, hopefully, takes a bit of pressure off you. Yeah, so I'm glad that you've got it where you need it and it sounds like you've got lots of support from the, the local store which is brilliant, really nice. Nice to be understood and for someone to know what the disease is and not have to explain it from start to finish. It's amazing that awareness is out there and fabulous news about their fundraising as well. That's obviously really vital and that's the sort of thing that, you know, that helps us to continue services like voice banking. We couldn't do it without the support of all of our amazing fundraisers as well. So, yeah, that's absolutely fabulous.

And Richard, if people want to bank their voice, who do they contact? Who do they need to get in touch with?

Richard: Well, they can, there are a variety of ways. So on the website MNDAssociation.org, we have a wealth, a wealth of information about voice banking. There's lots of stuff there now. And if you want to call Connect, and have a chat with them.

Steph: Fabulous, I just want to say a massive, massive thank you to Sue for joining us to chat about your experiences of voice banking and the difference it's made to you and your family as well, and speaking about it so openly and explaining what it means to you to have your voice banked and part of your personality within that voice.

Hopefully, that will just let other people know who are living with MND or families affected by MND that this service is there for their loved ones or for you yourself if you are living with MND. And, you know, please use it if it is something you think you want to. Like Richard said, it doesn't have to be that the voice is needed now. It can be there and then just parked and not thought about until maybe it needs to be used sporadically, or maybe never needs to be used. But, hopefully, this has raised some awareness.

Thank you Richard, your knowledge and sharing absolutely everything about what the service has been doing and how it's helped people and how, how you've worked with Sue has been brilliant as well so thank you both so much for joining us and for sharing both of your experiences and lots of lovely examples of how voice banking has helped lots of different people affected by MND.

Sue: Thank you.

Richard: Thank you. Thank you so much.

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