



MND Matters: Episode 40 – Preserving your voice

Steph

Welcome to MND Matters, brought to you by the MND Association. I'm joined today by Jen Benson, who's a speech and language therapist with over 20 years experience. We're going to be talking about voice and communication with MND, the changes that you might notice, the support, and also the options that are available, and how to plan ahead in a way that feels right for you, we're going to take a closer look at what voice banking is, when to think about starting, what to do if your voice has already changed, and how the technology has improved in recent years. Through this episode, we're going to be answering questions sent in by you, the MND community. So, thank you for sending those, and we want to make sure that you've got all the information you need about voice banking. Jen, thanks so much for joining us today. I feel like it's great to see you. No problem. Let's start by talking then about voice and how it links so much to our identity. It's something I think that so many of us can take for granted, until something changes, isn't it?

Jen

Yeah, I think I think you're exactly right with that bit about taking it for granted, and I think that's something that comes up all the time in discussions with people, either people with MND or people without MND. We definitely take our voices for granted, but if we just reflect for a minute on what our voices mean to us and what we, what we portray in our voices, so just as a really basic thing, listening to somebody's voice, you might be able to tell where they come from, where their community is, whether they sound like their family, who might know how old they are, roughly, and their gender by their voice. So we kind of carry all of that information about our identities within the sound of our voices, but then also there's that really personal element of your voice being a very much a part of you and very much how you express that identity, so I think it's really important to consider the importance of voices, and that's something that we very much do when we're talking about voice banking.

Steph

Yeah, absolutely, I think obviously it's a huge impact that people with MND, with 80% of people with MND experiencing some communication difficulties while living with the disease. Obviously, voice banking can help me can continue to communicate after their voice changes. When someone's diagnosed with MND, you might hear the term voice banking, but Jen just, just take us back to basics and explain what that exactly means. What is voice banking? What does it mean to a person if they're diagnosed with MND?

Jen

So voice banking is a term that we use when you record your voice to use in the future on a communication aid. So we know that many people with MND will at some point in their journey lose their ability to speak and their ability to communicate with their voice, and if that were to happen, we would be looking at providing them with a communication aid of some sort, and usually the way that we

would would operate that would be to type into a device, if you're still able, and to, and that device would then speak out for you, so rather than hearing the same voice as everybody else on that device, and rather than it being a voice that doesn't belong to you, voice banking technology was developed to be able to enable you to have your own voice coming out of your communication aid, so the process is really clever. It takes all of the sounds in the language that you use and it joins them all together and spits you out this wonderful voice at the other end that sounds like you. So basically it's a computerised replica of your voice that you could use on a communication device.

Steph

Lisa wrote into us. She wanted to know if voice banking starts upon diagnosis of MND.

Jen

So we would always recommend that people start their voice banking process as early as possible, so even if you're in that process of getting your diagnosis, which sometimes can take a little while to do, if you feel that you're able to do some recording and to bank your voice at that point, then we would definitely recommend that that's that's the way forward, and again, the conversation that that I tend to have, and I think what the conversation that we advocate other people having around voice banking is that it's like having an insurance policy for your voice, so if you do that recording, it doesn't cost you anything, you have nothing to lose, but then if it's there, if and when you need it, if as a result of MND, your voice goes, so that concept of vocal insurance was something that one of my people with MND said to me many, many years ago, and that's that's really stuck and rings true.

Steph

Yeah, that makes sense. And and Dawn also had a question. I know you're saying sort of bank voice as early as possible. She was asking about voice deterioration and what happens if there isn't enough voice footage to upload to create a voice bank if the voice has already deteriorated. What would happen then?

Jen

Yeah, so again, that situation that we see a lot with people whose voices are changing at different levels. So, there are a few things that we can look at. So, the first way that we can consider this is looking at pre-existing recordings. So, if you think of the digital age that we live in now, there are so many recordings of our voices in different places that we don't necessarily look for, so things like a voicemail message or a voice note, if you use those on your phone, but also older kind of forms of recordings, so things like your wedding video, if you had one of those many, many years ago, there may be lots of samples of your voice that we can extract from those videos, and then even if it's only a really small amount, we can loop those together to create a longer sample, which can then be uploaded, and with the progress and the technology as it is now, sometimes it can, it can be done with a really small amount of recording to get to that point, so that's definitely one option. There is another option called Voice Repair, who speak unique, who one of our voice banking providers offer, and what their voice repair service does is takes a voice that has perhaps started to change a little bit, and it kind of cleans up that audio signal, if you like, so it just takes away some of the slurring that you might experience, or some of those aspects that might just make you a little bit more difficult to understand, and just kind of, as I say, just kind of cleans up that signal, so it perhaps won't sound exactly like you used to sound before your voice changed, but it again is a good, a good suggestion, and a good place to try. And then the third option, if you really can't find any recordings and you're too far deteriorated with your voice to make any recordings for a repair, we would suggest considering voice donors as an option, and again, I think people worry about sounding exactly like somebody else if somebody, one person, gave you their voice, ooh am I just going to sound exactly like my sister, for example, and nobody's going to know who's who, but again, actually, what, what Speak Unique and other companies

as well can do is take two sets of voices, or sometimes three sets of voices, and blend them together to make a completely new voice. So, again, it won't be the voice that you had before, but if that's good enough for you, then that's potentially a good option too. So, yeah, lots of ways that we can consider that.

Steph

Yeah, that's great. Thanks, Jen. It's obviously really interesting to hear about all the advances as well, and you know, hopefully people can find an option that's that's suitable to them and right for them from the things that are out there.

Jen

For sure. And I think it's, it's the important thing is finding that option that suits you, and what one person might think of as a really great voice, and a really great recording, and a great voice bank. Another person might think, "Oh, that's just not for me. That doesn't sound like I wanted it to. That doesn't sound like I did before. And that's okay. It's absolutely okay. You can have a voice if you want one. If you try it and it doesn't suit you, you don't have to use it. You absolutely don't have to use it. Comes down to that personal choice, and that's different for everybody.

Steph

Jen, I know I said you worked in this field of speech and language therapists for 20 years. You've recorded your voice, I know you've recorded it a number of years ago, and you've recorded it much more recently. But with all the advancements in technology, what's the differences between your voice that you have recorded from a few years ago to what you've got recorded now, more recently?

Jen

So I'll be able to give you a demo of that, Steph. So I think the first one sounds significantly more robotic, it's got much less pitch variation, it sounds a bit slower, although I could probably tweak that a bit, and yeah, it just sounds more computerised and more robotic. The second one just sounds a lot more natural. It's got a lot more intonation to it. There's a lot more variation in the pitch, so it sounds a lot closer to what a human voice sounds like, rather than that robotic quality. So, I think there's those improvements are huge and will continue to get better and better as the technology improves. I think when sunlight strikes raindrops in the air, they act like a prism and form a rainbow. The rainbow is a division of white light into many beautiful colours. When sunlight strikes raindrops in the air, they act like a prism and form a rainbow. The rainbow is a division of white light into many beautiful colours.

Steph

It's very clear to see, as well, the advancements that have been made between the two voices.

Jen

Yeah, for sure, for sure. And the AI technology is really helping us with that, and yeah, there are some downsides to the AI technology, and I think we need to have a balanced view of how that's used, and it's really. Important to make sure that you have that discussion when you're choosing, choosing which provider to go with, but certainly the quality of the voices is improving all the time. It's great to see.

Steph

Yeah, absolutely. In terms of support and things for voice banking, we had a question from Aoife, who wanted to know support about support in Ireland and whether voice banking is funded and available there.

Jen

Yeah, as far as I know, so I know the MND Association covers Northern Ireland, but I'm also aware of the Irish MND Association, and I did my homework, had a quick look on their website in advance, and it looks as though they do also offer funding for voice banking in a similar way that that our Association does. So, yes, definitely, as far as I'm aware, but yeah, again, contact your local branch to find out more I would say.

Steph

Absolutely, and yeah, through our financial support programme here at the Association, we might be able to provide funding towards banking your voice and also technologies to help you communicate. So, some of this does need an assessment in advance from your healthcare professional. So, if you can have a chat with them first, your speech and language therapist, or anyone else involved, but you can also give our MND Connect Helpline a call as well, for more information on support that we might be able to give.

Jen

And just to say, as well. Sorry, Steph, to interrupt you, just to say, as well, but all of the voice banking providers, you can bank your voice completely free of charge, so it's not until you actually come to download it onto a device in order to use it, that the charge comes in, and that is covered by the Association, so you don't have to worry about the financial aspect of voice banking, you can just get on and do.

Steph

Yeah, that's really important. Thanks, Jen. Just touching back on we were talking quite a bit about, you know, the importance of recording your voices. Quickly as possible, when we reached out to the community before this episode, one of the main comments that came from quite a few people was the need to complete it quickly, but for quite a few people, including Anna, who wrote in found that waiting for an NHS appointment really slowed them down, and then had ultimately an impact on the quality of the voice that they got at the end of the process, so Jen, what should people do if they're worried about the time it's taking to see a speech and language therapist?

Jen

So I would say the first thing to do would be to speak to your care team, even if you've not seen the speech and language therapist yet, I would hope that you've had contact with somebody within your care team, so I would flag to them that you need that more urgent referral, perhaps into speech and language therapy, and ask them if they can help you to chase that up. So that's definitely one thing that you can do. We know that services are stretched, and that doesn't always help, but hopefully that that can give, give a push in the right direction. There's also that there's so much information on the Association website that can help you to just get on and do it yourself if you feel that you'd be able to make, make those voice banking recordings yourself. And again, all of the providers are very good at providing very accessible information, and I think something that we've always said is that you don't have to be a techy person to be able to do this, heavens knows, I'm not techy at all, and I've been managing to do this for, for a good few years now, and I think that's, I think the longer, the longer that we've been looking at voice banking, and the more that the processes have evolved, the easier the process has become, so it might be that you just feel that you can crack on and record yourself, or it might be that you have a family member who perhaps feels a little bit more confident and can support you with that process, and the other thing is that there is the option of accessing private speech and language therapy to help you with your voice banking, so as private therapists we belong to an association called the Association for Speech and Language Therapists in Independent Practice, and if you have a look online, you can search for a therapist local to you, or somebody that offers online services, and you may be able to access some private support to do that as well. So that's always an

option that's that's available to you. So I think there are lots of ways to not feel like it's the end of things if you haven't got that early referral into speech and language therapy, because there is lots of lots of help and support out there.

Steph

Thanks, Jen. And there was just a question from Megan as well about voice banking files, so she just wanted to know if they're kept after a person dies.

Jen

Yeah, that's a really good question, isn't it? Because I think this whole, this whole other aspect of voice banking is around that, leaving your digital legacy there, and I think that's something that that comes up in conversation a lot as well, that that there is that that legacy aspect of voice banking whereby your family may choose to listen to your recordings after you've passed away, and so those files are kept, so when you, when you do your original recordings with whichever provider you choose, you have to set up your normal sort of security type details and have a password there, so what we tend to talk about now is, excuse me, is having those, having those password details and choosing who to share those with. So, if it's yourself, you might want to think about whether you want your family to be able to hear your voice files after you've passed away, and if so, then you might choose to share those password details and those login details, and if you choose not to share, then again, that's that's your choice too, and something else that we've been looking at more recently within the community of practice is the whole, the whole consideration of the digital legacy, so again in this day at day and age of technology, we leave quite a lot of a digital legacy behind, so it's perhaps part of that broader conversation as well, in terms of how to family deal with somebody's, I don't know, whatsapp messages, or social media messages, and all of those kinds of aspects after, after somebody's passed away, so I think considering your voice banking and those leftover files, if you like, within that whole digital legacy framework is really helpful to consider, and certainly the idea of a digital will is something that's becoming more widely talked about now as well, which then obviously, like a, like a normal will, kind of leaves those instructions for families to know what to do after someone's passed away, so I think that's a really important conversation to have.

Steph

Yeah, that makes a lot of sense, Jen. Thank you. Another question came in from Sarah. It was about her dad, he'd had his voice banked and he's got it as an app on his tablet, but she said that nobody showed him how to use it. Now, unfortunately, he's got no use of his hands or fingers, so she's wondering now if it's useless if he's not going to be able to use it anymore.

Jen

It's absolutely not useless. So, there's definitely lots of ways that we can look at to communicate when somebody hasn't got the use of their hands and their arms. So, obviously, when we can use our hands and our arms, we tend to be typing onto a device, and that's what we would call direct access to your devices. When somebody's not able to use their hands to type, we would look at what we call other access methods, so that might be via something called eye gaze, where you look at the screen and you make selections with your eyes, or sometimes you can have a little mouse that's called a head mouse, and it's like a dot that sticks in the middle of your head, and you direct that to a keyboard on a screen and make selections that way, and sometimes we, we use what we call switches, so little buttons to press to activate selection of a particular letter or word or picture or whatever that is, and there are so many places that we can use switches, so whichever bit of someone still works really well and really consistently would be where we would try to put that switch. So sometimes if you've got a really tiny amount of movement left in your thumb, you can get in really light touch switch that you can activate that way, or sometimes people will use their heads to activate if they've got good head movement still.

So, there are lots and lots of ways that we can access assisted technology and communication technology that doesn't have to be with typing. So, I would say to Sarah to definitely make sure that her dad has a speech and language therapist, and to have that conversation with them about other ways of accessing technology, and there's lots of help and support out there to do that.

Steph

That's great. I think there's been so many advances in that in all types of technology, particularly voice banking technology, over the last few years. I mean, tell us a bit more about any improvements you see, and obviously we've got AI playing a part in lots of things as well.

Jen

Oh yeah, so if I think back to when I first started voice banking, which is probably, oh, 10 11 years ago now, the big thing that comes to mind is how long it took. So we were really talking about five or six hours of recording time at that point in time, which is a really big commitment to make, and particularly when you're, you're coming to terms with with your MND and living with your MND, and that fatigue that you're potentially experiencing trying to commit to getting that five or six hours of recording in was a really big deal, so the fact that we can now capture a voice in about 30 seconds feels like the biggest improvement that we had, and I think the different providers ask for different amounts of time. You can do a 32nd voice, you may not get as good a voice as if you put in perhaps even 20 to 30 minutes of recording, but definitely that that time that it takes is has been a massive, massive step forward. And again, thinking back to those, those kind of early days of voice banking, I can remember sitting with the first ever person that I banked the voice with, and it was really hard to capture the sound quality properly, and he lived in a property with lots of hard floors, because it was easier for him to get about in his wheelchair with having lots of hard floors, so we ended up putting lots of towels and blankets on floors to deaden the sound down, and at one point we even both of us kind of sat with blankets over our heads to try and get the sound to come out properly, so again I think it's things have progressed so significantly in that sphere as well that the actual process of capturing a voice is significantly easier than it was back back then, so again, those those have been the really big changes for me. I think the big introduction from AI has been in the naturalness of the voices, so again, thinking back, the banked voices were always great. They were always a really huge step forward, but if we think back to when we were first explaining them to people, we were saying they were like a computerised sound of your voice, you might sound a little bit robotic when you're talking, and it would be like your voice, but not exactly how your voice was before, and I think that's still relevant. I think we still acknowledge that there is that computerised quality to it, but with the introduction of AI, the voices are definitely becoming much more natural sounding, a bigger range of expression in the voices, which again was something that that we were missing with those earlier, earlier models, and I think that that whole idea of being able to use your voice to express your emotion is really, really important, and that has been the bit that it's been much more difficult for the. Technology to capture, but that's now really starting to come through with with the AI-generated voices, and even singing. There's, there's been a few people who have, who have put their singing voices on onto their AI recently, and that's a huge step forward too. So things really are changing. Technology moves very, very quickly, and it's great to see the advances in how we're working with voices. It's great.

Steph

Yeah, absolutely. Really positive changes there, and improvements for people, for sure. And Alissa said that she'd had her voice banked in 2023 with Speak Unique, so not too many years ago, but she wanted to know if it's possible to get it redone, because AI and technology have moved on so much even since then, and she wants to know if the voice is likely to be able to be improved now within that space of sort of three years? Imagine it's a yes?

Jen

I should think so. I would, I would say to Alice to definitely contact Speak Unique and ask them to have a look at the voice, they're a great company, they're really helpful, as are all of the providers, so yeah, I would pop them through an email and ask them if they've updated their software and can update that voice from there. The other thing that you can always do as well, when you have made recordings, they belong to you, so they are stored by the provider that you choose to go with, but those voices will always belong to you, so you can, if you fancied trying that voice into an AI voice agent, then you can request your voice files from Speak Unique, and they would send them to you, and then you could upload them onto something like Eleven Labs, and then you can compare what the voices sound like, which again is always a good option, if you feel that you've got the time to be able to do that, then comparing across more than one provider is another good way forward.

Steph

Yeah, absolutely. Like, if people have got the time that it gives them that ultimate control to decide what's right for them, doesn't it? And see if the wall. Absolutely. James was also asking about sort of with the pace of AI voice technology and how that's evolving. He wanted to know how you are adapting as speech and language therapist to keep up with this and also how you see your role evolving going forward to support patients with voice banking, obviously with no doubt new changes still to come. How do you feel that impacting your work and how you support people?

Jen

Yeah, so it's definitely a challenge to keep up with the technology, as well as everything else that we do in the day job. It's definitely a challenge to keep up with that technology, and for me, I think it's about knowing, knowing your crew, knowing your contacts, knowing your network. That's a really big part of it for me, and again, that's a little bit easier in the world of social media, so being able to follow lots of things on social media massively helps me to kind of keep abreast of changes and see what's going on, and also just just being able to chat to people within in the networks that we've got, so within the community of practice we've got a great network now of lots of different professionals all sharing that interest and that focus on on MND, so that's a really helpful resource to all of us to be able to share ideas, to be able to problem solve things that come up, and yeah, just to kind of keep abreast of things really, so that's definitely one of the big advantages for me is belonging to the professional communities and being able to share and talk about that information. I think some days I feel more like a recording technician than I do a speech and language therapist, and that's really pushing it for me in terms of of the technology, but again, just trying to trying to make sure that I make time to try things out for myself, because I don't feel like I can support people to my best of the best of my abilities if I haven't tried it out myself first. So, being able to do that is really helpful, and then I think just horizon scanning and just kind of being aware of what's going on out there in the world that might become applicable, so the kind of the mainstream approach to voices, if you like, is really changing, and some of those, the big companies are really getting on board with those kind of AI-generated voices that you might hear if you phone up a helpline, for example, or if you, if you need to go through a customer service agent on the phone to get to something, very often they're using AI-generated chatbot voices now, so it's, it's the same technology, so any advances that are made in that area I'm hoping will kind of have come on to to what we want to be able to do with with voices in the arena that support people as we do, so I think, yes, that's that horizon scanning and keeping a keeping an eye on on what's out there in the world is really important, and I think for me the really the most important bit of what I do as a speech and language therapist is still having that human connection with people, and that human connection of communication is always the number one most important thing that we do. So, it's finding the ways that take the technology and use that to embrace that communication and that connection, so that we don't lose the humanness of it, and I think that's that's perhaps becoming more of a challenge, but I think he's always really, really core and really central to what we do. So it's exciting times, but we have to keep to that core. I think.

Steph

yeah, absolutely, that sounds like a really good balance as well to make sure people get what they need, but you still keeping on top of all the things that could be a huge benefit with developments as well in technology, and in terms of the future of voice banking, quite a wide, wide sort of space to have a thinking, but what, what do you see that future to be? Obviously, lots of advancements with AI and technologies to come still, but how do you see things going in the future?

Jen

Oh, I think it's really exciting at the moment. So, as we just touched on before, I think the more commercial use of voices and of voice recording technology seems to be, be that's becoming a really big thing at the moment. So, again, when I was, I was horizon scamming recently as part of some CPD that I was doing for the community of practice. I was looking at some of the big tech companies to see what they're doing with voices, so Microsoft, for example, have a new, a new voice system called Microsoft Azure, and that is their AI equivalent, which I think will become the competitor to Eleven Labs at some point, particularly given the magnitude of a company like, like Microsoft, and what I really liked about reading their content was that they seem to be dealing with things in a very ethical way, and again, I think that's always something that we have to be aware of when we're thinking about AI, is where those ethics do sit, and I liked that Microsoft, in particular, seemed to be kind of holding back on really delivering out their commercial side of things and using it just with their really big clients as it develops but again hopefully that will then translate into the kind of voice technology that we can use as as people looking for voice banking which is really exciting and a lot of the communication devices that we use are Windows-based software, so it would make sense for them to kind of have come in that direction, but again, even things like my Alexa, a couple of weeks ago, asked me if, if I wanted her to use a more natural voice, all right, then go for it. Again, had a look into that, and there's something that Amazon's offering is called Amazon Polly, so again, with the might of these tech giants behind this kind of technology developing, I think it's really exciting to see kind of where it takes us, really. So see what happens, watch this space,

Steph

maybe in even sooner period of time to find out, yeah, what's been what's been happening. So, just in summary, Jen, what are the top three things that people should do right now if they're even thinking about voice banking?

Jen

So, I would say the number one thing that you can do is just make some recordings of your voice, and it doesn't matter what you record, and it doesn't matter how you record it, so you can use a voice memo on your phone, for example, or if you have a computer in front of you, you can sit and record onto onto a voice recorder on on your computer, but just capture something so that you've got that there ready to record, ready to use if you do want to bank your voice, and that kind of perhaps takes away some of the worry about am I going to lose it before I get a chance to do it. So just record something that would be my number one thing. I would look at the information that's available on the MND website, there's lots of good information there, and speak to the the MND Connect team if you have any questions about that as well. They're a wealth of information and can definitely signpost you in the in the right direction, but also talk about it with with your care team, and again, people will be at different stages, I'm sure, of how much professional input they've got, but whoever you've got, whoever is coming out to see you, whether that's your MND nurse, whether that's your occupational therapist, chat to them about what you want to achieve with your voice banking and get it up there on your agenda, so that you feel that you're in control of that and in charge of that.

Steph

Brilliant, thanks, Jen, and thanks so much for joining us. And to echo what Jen said, if anyone listening needs support with voice banking or has any questions, then they can either contact their speech and language therapist or, of course, our MND Connect helpline as well. Thanks so much again, Jen, for joining us.

Jen

Thank you.