

Coronavirus and MND Ask the Experts 30/06/2020

Exploring the impact on speech and communication services

This content provides the main points from a live interview held on 30 June 2020.

See the video of the interview in *Ask the Experts* at:

www.mndassociation.org/coronavirus

Introduction

Nick:

Hello everybody thank you for taking the time to watch this video today. My name is Nick Goldup I'm the Director of Care Improvement at the MND Association. As you may have seen through our previous videos, we at the MND Association decided to engage with our wonderful healthcare professionals, supporting people living with MND across the country to understand the issues and changes faced during these uncertain times by services.

In this fourth video, we are lucky to have three terrific guests from the world of speech and language therapy, who I am sure many of you will already know.

Firstly Zoe Clarke, Zoe is a Clinical Scientist with the Barnsley Assistive Technology Team and lead for NHS England for specialised environmental controls services.

Secondly, we have Julie Atkinson, Speech and Language therapist from the Access to Communication and Technology Centre, at the West Midlands specialised services for AAC and EC. Julie is also the NHS England Lead for AAC services.

Thirdly we have Richard Cave, Speech and Language Therapist from the Royal hospital for Neuro Disability in Putney which is also a specialised service for AAC and he also works with the MND Association on a number of technology projects.

Welcome to you all.

Question 1: For those who aren't familiar with the speech and language therapist role, the structure of services or acronyms used, could you give us a quick summary?

Richard:

Yes sure, firstly I'd just like to say I think these MND Association videos with your panels have been incredibly useful. I have watched the others and I have referred clients to them. I think in these difficult times having this as an accessible, useful source of information to provide clarity and direction is actually very useful.

So what is a speech and language therapist? We work with many different people and one important area is to help people to communicate, what they say and their everyday needs. Another aspect is to help advise if it gets difficult to eat and drink, or there's a worry about it. And it's a sad fact that many people living with MND can progressively lose the power of speech as well as movement and we work with them, their significant others, friends and colleagues, to help maximise their communication as things change. The priority is for people living with MND to still be able to communicate what they want to say, share the important things, keep in touch with everybody and maintain friends and social networks.

In the early stages of MND, voice quality or strength may change and just simple things like a quieter environment, with the radio off for example, can help. Or perhaps additional tools such as a voice amplifier, pen and paper, or a tablet to help speak a message. Anything that supports communication in this way is called AAC, which stands for augmented and alternative communication. Augmentative is to supplement; alternative is to replace. It's really just a fancy term for a device or method that helps with communication. Be it pen and paper, an alphabet chart, all the way to high technology stuff like an eye gaze system, that allows somebody to type messages using their eye movement alone.

I think the important thing to remember here is that MND is a journey. As speech changes or there is worry about eating and drinking, it's important to work with speech and language therapists as early as possible. Even if nothing has changed yet, but just to plan for the future, for how things may or may not go. And to understand what AAC is, what options there are and how they may help.

Your local speech and language therapist will work with you initially. If things get significantly more difficult or complex, with voice loss or difficulty with movement, your local speech therapist can refer you to a specialist AAC service for help and guidance on equipment.

Another term is EC, or environmental controls. These are systems that help people with physical difficulty maintain independence as far as possible. For example, something that would help you switch the lights on or off, change TV channels, operate a fan on a very hot day, or make yourself more comfortable in a bed or chair. These environmental control services are sometimes part of specialist AAC services and sometimes separate, depending on where you live.

If you want to find out more about environmental control or AAC, or you have a worry about your eating or drinking, ask your speech and language therapist, or in terms of EC, your occupational therapist. Or indeed, any professional that's working with you, so they can help or refer you to another team.

Zoe:

In terms of environmental control, I'd add I that it would be a local occupational therapist identifying or speaking to people about how things have changed with physical access, such as using their television remote or perhaps switching on their tablet. The occupational therapist may have suggestions for that or might get in touch with the specialised service around that. It's a big part of the work of the multidisciplinary team to come up with those solutions.

Julie:

I'd just to like to bring in that MND Association advisers make quite a lot of referrals through our services as well. They are very aware of where we are and how to get in touch with us.

Question 2: What's changed most for you in your team during this period?

Zoe:

For my team and for teams nationally, both in terms of specialised EC and AAC, the biggest change had been being unable to see clients face to face. Generally, this would be done in their own homes or in their own environment and that's quiet a big change for us. When assessing for EC in people's homes it's really beneficial to be able to see where people are, what they want to be able to do and what equipment they have got already. Not being in that environment to do the assessment has been a little bit more challenging.

My teams been able to support our hospital trust in response to the pandemic, which means some of our staff have been redeployed, but we have been able to continue our services. In most cases we have been doing that remotely, so we've been taking new referrals and had a remote procedure using telephone and video calls to undertake assessment. Then we've been couriering equipment out and further video assessment to support how to use that technology.

There has been success with this, but there are also challenges because the process isn't ideal for everyone. Some people needed set up in terms of being to have and use a video call, then suddenly this new piece of technology comes into the house and they're trying to set that up too. Even with quite a lot of instruction, we are just not there to press the buttons ourselves. We have been able to meet some goals and where we haven't met all of them, we've got a system of putting them on hold and regularly reviewing them as the situation evolves, which it is doing all the time.

In addition to our new referrals, both EC and AAC services follow a kind of maintenance service for people who've got our equipment. Again, this is just as

important as those new assessments because people are using their equipment all the time, so we provide a full response of preventative maintenance. Faults have been supported as much as possible, with a remote first approach. Recently, as a team and as in national discussions, we've been looking at remote maintenance to help people avoid faults before they come up, which is interesting and definitely testing some new ways of working.

If we get to a point where we do need to visit, we follow NHS Community guidance to carefully evaluate if a visit can take place safely, whether we have done everything possible remotely, and if people are happy for us to visit – as obviously it's a two way thing if we are coming into their environment. Then we're taking mitigations to minimise contact once we're on site. For example, doing what we can outside on the drive, swapping things over the doorway, cleaning items down before putting them back in the house. It's worked quite well and made us a bit more creative. We're aware that in someone's home we need to take precautions to be a good distance away and obviously using appropriate PPE, but there has been some variation around the country.

Our teams been able to support, a lot remotely, but in some cases there's been redeployment. We have been able to evaluate high priority referrals and have been able to respond to all their fault calls. But it is a big change to go to phone calls from face to face, which we are all finding introduces a lot of challenges, but a lot of learning as well.

Julie:

Our experience is pretty similar. My team had more redeployment I think than Zoe's team. We are starting to get people back now, but we have maybe been a little bit slower to start doing the remote work. We are now up and running and really moving forward. When we talk about remote we aren't just talking about this (video calling) kind of technology, it also includes phone calls and good 'old fashioned' technology.

Question 3: How have referrals to AAC and EC been affected during the current period and how do you see this impacting services going forward?

Julie:

Referrals to our specialised AAC and EC services for people with MND usually come from speech therapists, occupational therapists or the MND Association. At the beginning of this pandemic, referral rates were significantly reduced and we could assume many reasons. We know that staff from the NHS have been redeployed to those critical hospitals, to treat very poorly coronavirus patients and to ensure that those ready for rehab go home to free up the beds. So perhaps staff who normally make referrals have been redeployed. Referrers might have thought our services were closed or that we weren't taking referrals because we couldn't see people face to face. Importantly, there might be some people with MND that just feel this isn't the right time to ask to be referred - we have to think about this and that they might be really worried about someone coming into their home to see them in person.

As Zoe's emphasised, we are doing 'remote first' appointments, so we do need to reassure people about that.

The last couple of weeks, a steady stream of people with MND and other conditions have been referred to us. We've been working really hard to let referrer's know that we are open for business, taking referrals and seeing people. I think moving forward in terms of service provision, each NHS trust has been developing its own recovery plan to get services going again. A lot of services have not been able to see anywhere near the number of patients that we would normally see, so we're balancing that recovery plan while heeding government advice about who we are able to see (using the current community guidance that Zoe's mentioned).

I think we are anticipating a gradual return to business as usual, although 'usual' may look slightly different. There might be more technology and remote appointments within that. As staff return to their permanent roles as lockdown eases, and hopefully people feel more comfortable around other people, we might get more referrals. We have continued regular contact with the AAC services and the EC services we normally meet, and Zoe and I have a good look together so we learn what works best from each other. We're trying to avoid reinventing the wheel and duplicating things that might have been a challenge or already done by other services earlier in the process.

Using remote first is important, ringing people up, talking difficulties through, see what we can help with over the phone then using video conferencing. There are different platforms, like Facetime or Whatsapp if people have those, as well as more formal Microsoft Teams. Using this technology, we can see home environments, including computers, equipment, TVs and how people can or cannot access them. The really important message for patients is that we are still open and getting equipment out to them. We are carrying out progress reviews and repairing faulty equipment, but perhaps not in our usual ways. Thinking about making some changes to practice, means that we will keep moving forward because some changes have been really positive. We may even identify aspects of service delivery that we haven't really missed and might not need to reinstate in the future.

Question 4: How is the current situation regarding access to services such as voice banking, as well as other communication aids and environmental controls?

Richard:

I just want to emphasise that if a person living with MND, significant other or family friend wants to find out more we are still open and where local speech and language therapists are concerned, we are also still open for referrals. Regardless of Covid, MND is still progressing and those problems have not changed. Of course it would be interesting to understand why there was a drop off in referrals, but there are probably multiple reasons.

We are changing our practice and doing lots of voice banking support. All of that is online now so we don't visit people, we give them video support, and we train speech and language therapists and other professionals working with MND. If they would like to understand about voice banking and get their own voice banked to demo the provision to their patients, we do that. Just in July we gave training to about 40 professionals online to create their own voice bank and plan a similar amount in August. So professionals should get in touch.

I've been forced into different practice with remote video support. Some of it has worked out really well, other parts are challenging. But I'm providing video support every day, as I'm sure all of us are. The MND Association are still loaning iPad's, Lightwriters, headsets and remote loan of Apps and other things. The only downside with the MND Association loan service is that unlike the drop in referrals talked about earlier, conversely we have been inundated. We actually had to push our response – there's just a lot of demand out there. Maybe because everything can be done remotely. Loaning equipment from the MND Association has its own issues, as local statutory services should be funding some of that equipment, but given where we are and the usual urgency with MND, plus covid too, we're working hard to help people right now. That's pretty much where we are.

Question 6: Where staff have been redeployed, has there been any impact on service and if so, how do people get support?

Zoe:

Nationally, there has been considerable variation within the specialized teams in terms of redeployment and how people have been supporting our Trusts. Each local trusts responding to Covid in their own area has had different demands on services.

Within our team we've been able to support our local speech and language therapy team, with a couple of members of our staff doing some days for them each week. We've also supported within the hospital. Our inhouse tech team has supported the estates team within the Trust, and the clinical engineering in terms of new equipment. There was a large influx of ventilators and things like that, which they helped get tested and into place quickly. This helped things to be as efficient as possible in the general running of the Trust.

A lot of other local services have been affected by redeployment, or Covid in general, and reset priorities in terms of activity and focus. Again, this may have affected referrals that would normally feed into us. Around the country there's been a lot redeployment in terms of specialised services, but even with skeleton service staff referrals are appropriately prioritised where possible.

In some cases, it's been possible for a temporary system to tackle an immediate problem. For example, a pager with an adapted switch to call for attention. This may not be the best long term solution, but can help in the short term.

With fault response, it's about ensuring that people with equipment can keep things going. Where we've had a few less fault calls, we are conscious that we might get a

sudden influx of work at some point. We're trying to stay on top of what can now, so we're ready when people decide it's time to sort out a fault that they have managed so far. There's been a lot of support and understanding during the Covid response. People will start using the services more again and when they choose to do this will vary.

I can echo that we've remained open too. Despite the drop in referrals, there's still been a steady stream. At the beginning our team did wonder if we would get a complete stop due to the situation, but it has been reassuring that we kept going.

Julie:

It would be very unusual for an entire team to be redeployed. Although some teams are left with fewer staff, there's always going to be somebody there, either in the local speech therapy team or the specialised services you can seek support from. Many staff are working from home at the moment, as one of the issues with social distancing is that we can't have the same number of staff in the building. That means when you call the office for support, you may have to wait for somebody to get back to you because the right contact isn't physically in the office and a message has to be passed on.

If you need support with equipment, contact the service who provided the item, such as your local speech and language therapy unit, the MND Association or a specialised AAC or EC service. You can even contact the equipment manufacturer, as they're all still working, with EC systems particularly, as these are maintained by contractors for the NHS. They're doing what we're doing; remote first and then visits only after careful consultation with us and the patient, after risk evaluation.

We would hope that people at home have specific contact numbers for whoever maintains their equipment. If not then contact the main service direct. We're not just talking equipment faults here, as with MND your condition does change, speech changes, movement changes. If you feel something has changed that stops makes it more difficult to use the equipment provided, do contact us. There's likely to be some adjustment to help you keep using it, which is important to know.

In terms of the communication aids a lot of the companies are putting lots of resource materials on their websites, including webinars like this from the MND Association. AAC companies have always offered remote support, so they have always had a real strength with that anyway, such as dialling in to communication aids and accessing them remotely. Nothing has changed there, other than some working at home perhaps or furloughed, but these companies are still able to support. So even though staff may have been redeployed or company staff furloughed, we're still seeing people and moving forward with equipment.

Prior to Covid, the specialized AAC and EC services were beginning to develop a website with lots of resources on for patients, families and professionals. We are really pleased in these challenging times to have launched this. Perhaps not quite as

we would have wanted it, but we have a version ready. It offers low tech paper based resources for people to try, also coronavirus resources as well.

You can find that support online at: www.assistivetechology.org.uk We hope to get an NHS domain name for it, but getting information out there was our first priority.

Question 7: Have you been able to embrace new advances, as so much is happening with new technology at the moment?

Richard:

Yes, we're looking at this in two ways. First, the actual experience of people living with MND through Covid and reviewing technology they've been using to see how easy or difficult it has been. As a vulnerable group, people with MND (regardless of Covid), may not be able to leave their homes easily and haven't been able to do this at all during the pandemic. With the main age group of MND between 55 and 75, there is variation in those who are really good with technology and some who find it a bit more challenging. And this really matters to help people communicate with loved ones, get online, order food and more. We discovered that for many people, the technology feels complex and they are just not used to it. From an MND Association perspective, we have been talking with Microsoft and Google to offer feedback as the future is clearly going to include more tech for communication. So how can we include everybody?

In a related project, we are also supporting the Ufonia project with Google to help people with changed speech, or 'dysarthria' to still be able to use voice assistance stuff like Alexa or Google Assistant. It's difficult for these platforms to understand speech that has changed or slurring of words, but if they could, it would unlock everything that voice assistance can do for the rest of us. It means assistance to turn lights on and off, change TV channels, get directions, listen to music and more. Those who would benefit the most are blocked if their speech is different to what's expected, so we're helping to train Google Assistant to understand how slurred speech actually sounds. We are inviting anybody to help regardless of diagnosis, MND or any other, just so long as they are adult and they consent to read some phrases, to help train Google Assistant. It's too early for results yet, but worth doing.

Nick:

I think that's very exciting. Technology and the way it can support people with MND is something that we are fully behind and need to support. Thank you for that summary Richard.

Zoe:

In terms of environmental controls, it's easy to underestimate how important it is to be able to control your television or your lighting independently. In the winter when it gets dark at 4pm and you don't have a carer calling until 5pm and you are sat in the dark, it's a massive impact on your quality of life and independence if you are able to

do those things yourself. The advance in technology and research like Richard has just alluded to is quite exciting, and how the world of EC and AAC will evolve.

Question 8: Do you think we will carry on influencing the changes we've seen over this lockdown period?

Zoe:

Yes. As a team and in national discussions, we've identified benefits, particularly around remote assessment. This period has given us opportunity to test, use and push with remote more than in previous operation. We've had a chance to evaluate what is good and perhaps not so good. Now we have to look at how we continue to integrate remote support, not just video but telephone, and how we make visits as short and efficient as possible, which I think is beneficial anyway. People with a variety of conditions find a long visit tiring, so improving efficiency and flexibility as much as possible is valuable for those we see.

Feedback from clients, carers and family has also shown they feel quite empowered. I think sometimes, not intentionally, we go out to someone's house and it's easy to assume knowledge because we know something ourselves. We might demonstrate something too quickly and it's not really understood. Because we have been explaining remotely and sending instructions or videos of what to do, people have had to do a bit more themselves. We've ensured they feel supported with that, but they have found it empowering and helped them understand more about how things work. Perhaps it's also sparked a bit more curiosity to think, 'Now I've seen it can do that, what else can it do?' We have found that really important to feed into lessons learnt.

We have also identified situations where these changes haven't worked as well, but we are putting all that into informing our future best practice.

Nick:

Thank you Zoe and thank you everyone. I have really enjoyed our discussion today. We have been very lucky to have your time in answering my questions. My colleagues within the care team will bring together all the key points from today's session and communicate them through the MND Association website, so please do take a look at that over coming days and I'm sure we'll be able to cascade this out through social media as well.

We have a specific coronavirus hub on our MND Association website so do have a look there at: www.mndassociation.org/coronavirus or access this through the homepage. Also take the time to speak to some of our staff through our MND Connect helpline: 0808 8026262 mndconnect@mndassociation.org for questions you may have on anything that we talked about today or anything else for that matter. Thank you everyone and please do take care.