



RCSLT and MND webinar – Living with motor neurone disease: supporting speech, communication and swallowing
Tuesday, 5th June 2018

Claire Moser, Policy Adviser, RCSLT

Good afternoon everyone, and welcome to today's webinar, 'Living with Motor Neurone Disease: supporting speech, communication and swallowing'. Thank you all very much for joining us today. If you use Twitter, please do join the conversation using the Twitter hashtag #rcsltwebinar and #motorneuronedisease.

My name is Claire Moser, and I am the policy adviser here at the Royal College of Speech and Language Therapists. I will be chairing today. I am absolutely delighted to welcome and introduce our two speakers. Firstly, we will have Steven Bloch, senior lecturer in acquired communication disorders at University College, London. Secondly, we will have Jennifer Bedford, head of partnerships at the Motor Neurone Disease Association.

Today's webinar will be 45 minutes long, and there will be time for questions at the end. During the webinar, you can use the Q&A button on your screen to submit a question for the panel. We may not be able to answer all the questions in this session, but we will do our best to make sure that an answer goes online. If you have a technical problem with sound or vision, please use the chat button to send a message to Kaleigh, who is on hand to help today.

This event is being recorded, and it will go online on the RCSLT website as soon as possible after the event. Also, your feedback is very important to us, so please do fill out the very short survey which will pop up on your screen at the end.

In 45 minutes from now, we hope that you will be familiar with the needs of people with motor neurone disease, understand how speech and language therapy can help, understand the support that the Motor Neurone Disease Association provides and the support that RCSLT offers its members in this field.

So, without further ado, I'm now going to hand over to Steven.

Steven Bloch, Senior Lecturer in Acquired Communication Disorders, University College London

Hello, thank you very much for this wonderful opportunity to present an overview of how speech and language therapists can support speech, communication and swallowing for people living with MND. We've only got 12 minutes, so it's going to be concise but hopefully informative. I'll be answering some of the submitted questions during the presentation, and others will be dealt with by signposting and additional resources. So, by the end of this presentation, you should be familiar with how MND impacts on people's speech, communication and swallowing, what SLTs can do to support people living with MND in these areas, and sources of more specialist advice.

So, how can MND affect a person's speech? Well, the primary disorder of speech is known as 'dysarthria' – this is a neurogenic motor speech impairment characterised by slow, weak, imprecise and/or uncoordinated movements of the speech musculature. It's caused by variable damage to either the upper or lower motor neurones but typically both upper and lower, leading to a mixed spastic and flaccid dysarthria. All levels of speech can be affected, commonly oral sound production, voice, breathing and nasality, and the early signs are mild voice problems leading to more generalised slurred speech.

In a very recent study, looking at bulbar symptoms in MND which commonly lead to speech and swallowing problems, about 30 patients were studied over a two-year period, and their speech

remained adequate, on average, for about 18 months from first bulbar symptoms; but thereafter it deteriorated rapidly, with over 60% of the participants in that two -year study using AAC, different forms of communication technology.

The functional outcome of dysarthric speech is its effect on intelligibility. This is a two-feature construct – the speaker and the listener or partner, both people play a part in how intelligibility works. How well someone is understood can vary during conversation at different times of the day. The context really does matter – the more you know someone, the more intelligible you'll find them.

So, what can SLT do to support speech?

The first thing is to establish how the person feels about their speech and how their family feel. Even if they're affected by small change, this needs to be acknowledged and worked with. We need to recognise existing abilities, treat these skills with therapeutic intervention. What's working well between a couple, that's important as well as what's going wrong. It's worth observing and discussing.

There is a need to minimise barriers to intelligibility, setting the scene and ensuring listening is maximised. This is often neglected; almost seen as advice giving at the end of a session. There may be value in treating this as therapeutically as any other intervention.

We need to get to know someone, building rapport, establishing relationship. The most effective therapy often comes from this relationship, particularly at the start of the SLT process, and it shouldn't be taken for granted. Again, the most experienced and skilled clinicians appear to do this almost effortlessly, but it is a skill that can be developed.

Finally, small changes to behaviour. Now, there's currently no evidence to support exercises for dysarthria, like LSVT or a motor exercises or articulation treatment. And, despite the high incidence of muscle weakness in individuals with MND, the effects of exercising this population are just not well understood. We don't know what works. We don't know if exercises can help, or we don't know if they might have a detrimental effect. Now, there is some early evidence for the effect of Expiratory Muscle Strength Training for respiration and swallowing and dysphagia, and we'll look at that later.

How can MND affect communication? Speech is not the same as communication, speech is the production of sound for communication, but communication is how meaning is conveyed. It's a complex thing. It's not just about the successful transfer of messages.

One of the most important impacts is reduced opportunities for participation. If people are unable to work, go shopping, travel, then they have less going on in their lives and simply less to talk about. But, participation isn't being just presented with social opportunities; it's doing things that one actually wants to do, so the risk here is one of social isolation.

There is also tendency to focus on the here and now, less on more abstract features such as telling news or stories, joking or teasing – many of the things that make us who we are. There is the risk that the here and now becomes dominated by problem solving and healthcare. If this can be anticipated, then it can be addressed. Inevitably, roles are altered and this impacts on relationships and on intimacy, particularly with partners and children.

Finally, there's the effect of cognition, and this has been heavily underestimated by clinicians for many years, with current evidence suggesting that almost 50% of people with MND may experience some level of cognitive change. This can be executive functioning, language and behaviour. Rather than go into detail here, I would strongly recommend that everyone refers to the excellent MND Association's booklet for professionals on cognitive change, Frontotemporal Dementia and MND, and we'll provide a link for this at the end.

So, what is it that SLTs can do to support communication? Here's a basic framework that I've used in my own work. It considers past, present and future.

In terms of past, what we've been thinking about here is establishing the person's life before MND – what they've done, who they've been. It's all about identity and relationships, and it may also lead to legacy work, allowing people to recall their lives in order to preserve their lives for the future, particularly for their children. And there are some excellent resources – recordmenow.org, life history work, digital legacies – all of which enable people to think about their pasts as ways of supporting themselves and their families in the future.

For the present, we're trying to establish what people are doing well, what their needs actually are and, importantly, their social worlds in terms of who they interact with and what relationships are important to them. This is ongoing assessment of speech, language, cognition, but also real communication needs and wants. And it's particularly important to involve significant others in this process.

Thirdly, there's the future. We'll look at AAC coming up, but there's a lot of anticipatory work that can go on here in terms of planning for AAC, in terms of emotional support, technical and ongoing, voice banking which can take a minimum of six to eight hours to record over a period time, usually weeks or months. Voice banking is currently a very hot topic, and the MND Association are heavily invested in supporting people with voice and message banking. There's an excellent project work going on with Richard Cave in association with the MND Association.

Current research suggests that many people report they haven't been provided with the information about voice banking in order to make a timely decision about it and, as a result, haven't banked their voices. So, it's important this is done as soon as possible as appropriate after diagnosis. However, we've got to remember that it's a very individualised and personal decision and is not necessarily the right thing for everybody.

In terms of AAC, there's a whole range of AAC assistance that can be used by people with MND, electronic as well as non-electronic. Sometimes, it's simpler just to use pen and paper rather than go for high technology but, equally, high technology can resolve a number of issues, particularly with respect to access systems like 'Eye Gaze'. In fact, physical access to the system is really the key. We need to work with occupational therapists and physios, as well as technologists and rehab assistants and engineers.

AAC Hubs in the UK are key for more complex cases. There's also great interest in brain computer interface access at the moment, but this is some way off functional use. For further information about AAC, it's worth looking at the Communication Matters website, as well as the Best Practice for Professionals Resource on the Motor Neurone Disease Association website.

Whilst this next slide can look somewhat overwhelming, I thought it would be useful just to remind ourselves that apps are now really accessible to people and familiar to people. This wheel of AAC apps, coming from the excellent Call Centre in Scotland, is just a reminder of the whole range of difference resources that are out there for people. What I particularly like about this resource is that it pinpoints different types of apps for different types of communication need, and it's well worth looking at the Call Centre Scotland website for more information about the types of apps available.

So, in summary, with respect to speech and communication interventions, we've got a whole range of interventions from normal speech all the way through to severely reduced physical access to AAC. And there's a huge amount that could be done early on as well as throughout the process of supporting somebody with motor neurone disease in terms of their speech.

So, how can MND affect eating, drinking and swallowing? Well, dysphagia emerges in more than 80% of patients during the advanced phases of the disease. We know that a whole range of issues are experienced – aspiration, chest infections, weight loss in association with muscle loss and atrophy, nutrition and hydration, which can lead to confusion as well as urinary tract infection.

There's an issue of saliva management, in which people can experience difficulties both in thin saliva as well as thick and tenacious saliva, mealtimes and sociability and the psychological impact and fear of choking which is a very real fear, a fear of suffocation or blockage of breathing.

What can SLTs do to support eating, drinking and swallowing? Liaise with specialist nurses, OTs, GPs and dieticians for oral hygiene, care and promotion. Postural change and diet, again there's early evidence that there may be relevance for expiratory muscle strength training which can improve swallowing and respiratory outcomes, and I'll give the references to that work at the end. There's saliva management, and there's non-oral feeding and PEG management. I'll also refer you to the new MyTube online resource, which I feel offers a really helpful indication for patients, carers and professionals, as to the journey that people go through with respect to non-oral feeding.

There's other specialist advice, in terms of the AAC Hubs' specialist advisors, the MND Association and Regional Care Advisers, as well as a huge range of resources on the MND website.

Finally, there are six points that I'd like to stress:

1. MND is a complex condition that demands a strong multidisciplinary approach.
2. SLTs are specialists in communication and swallowing, and they're integral to the team and long-term care.
3. AAC is important, but technology can't replace human face-to-face communication and interaction.
4. There's anticipatory work that could be done in all areas.
5. Communication and eating are highly social activities, and intervention should involve family and friends.
6. Working with people with MND can be very rewarding, but also emotionally demanding; consider your own mental wellbeing as a therapist as well as that of your patient and their carers.

Finally, I'd like to extend my thanks to the following people who have helped me with this presentation for this webinar. Now, I'd like to hand over to my colleague, Jennifer Bedford.

Jennifer Bedford, Head of Partnerships, Motor Neurone Disease Association

I'm delighted to be speaking to you today, and I hope to highlight today how the Association can support you and help you support the people in your care. The slide I've started with here is an infographic about MND. The key statistics illustrate the devastating effects of MND and the rapidity of the condition; it kills a third of people within a year of diagnosis and half within two years, and this makes the need for swift anticipatory care very important.

Today, I will look at six ways in which the MND Association can help you – through remote support, local support, equipment and loan, communication-specific support, grants and education and campaigns.

For remote support, the association has a comprehensive website. Obviously, this is a service that is available 24 hours a day, 7 days a week, and it carries a vast amount of information, from "What is MND?" through to subject-specific contents and the latest research into the disease. To answer a question that was tabled earlier, there's also an easier to read version of the introduction to MND.

Much of what I cover today will be found on the website, and Steven's already referred you to it previously, and you'll find that I direct it to you frequently. The website has an area dedicated to health and social care professionals, where you can find information sheets on individual subjects such as managing saliva problems in motor neurone disease and booklets with a wider scope, e.g.

'Motor Neurone Disease: A Guide for GPs and Primary Care Teams'. There's also an end-of-life guide which is a very good resource to have a look at too. You will also find links to online learning in this section, with courses for care workers and two endorsed by the RCGP which are free, you just need to register to use them.

You might recommend the websites to the patients in your care, as there is a comprehensive range of information sheets and resources to help and support them too. In addition, it will put them in touch with us at the association and the wider support network and services it offers.

MND Connect is where you need to go to talk to an actual human being. MND Connect is the association's information and support service. You will see the number and email address for it on the slide. It is for people living with MND, people affected by MND (so that means carers and families) and also health and social care professionals like yourselves. You could use the service for yourself or direct a person in your care to it.

Connect advisers are trained and experienced, and they can give information about MND and symptom management, emotional, practical support. They can provide contact details for local support which might include an Association Visitor (which we will call 'AV') a local branch or group or a Regional Care Development Adviser (which we call an 'RCDA'). They can also give further information about how the association can help you and signpost you to appropriate services, both internal to the association and externally.

For local supports, if you're looking for support on the ground, the association has representatives throughout England, Wales and Northern Ireland. These are Regional Care Development Advisers. Their role includes working with you as health and social care staff to support the improvement of local services for people with MND and their families. Our RCDAs raise awareness of MND and organise training and study opportunities for health and social care staff. They also work with managers to influence the way services are provided. Think of them as your allies, and you can find details of the RCDA in your patch on the Association website.

You will be keen to give your patients the best support you can, and RCDAs can help. They make sure that people living with MND and their families receive support and information, through local support networks, and can put them in touch with an Association Visitor, which brings me onto that role.

Our Association Visitors are carefully selected volunteers that have undergone a thorough training programme. Often, they have direct experience of MND themselves. Visitors are based in local communities and usually have contact with people over the phone, via email or will visit them in their own home. It depends completely on the needs and wants of the person. A Visitor can offer people with MND and their carers and families emotional support, giving people just the opportunity to talk about feelings or practical help, by advising what support is available in the area.

The Association can also help with an equipment loan. We can usually help with loans of rise and recline armchairs, portable suction units and communication aids, and this includes voice banking equipment. A health and social care professional must assess a person's need for equipment and explore funding through statutory services before making an application. If there is a delay in receiving support through statutory services, we would look to provide assistance as a short-term measure. The same can be said if a delay in provision by the statutory services is unacceptable, based on the needs of the person with MND. Any application, as I say, must be made by a health and social care professional.

In terms of communication support specifically, the association recognises the importance of communication for people living with MND. Many of our members have described losing the ability to communicate as the worst thing about MND. "*Voice banking*" was the most searched term on our website in 2017, so we have a communication aid service, which is led by a dedicated communication aid coordinator, Matthew Hollis. You can see the email at the bottom of the slide.

In terms of equipment loan, where statutory services are being too slow or there is insufficient provision, we can loan equipment such as text-to-speech devices, headset microphones or the technology required for voice banking. There are a limited number of other types of equipment for hire too, such as switches, voice amplifiers, software grids like Grid 2, and eye gaze cameras. For any specialist information of what is available, it is best to contact the communication aid coordinator. There is a specific voice bank support grant which can be applied for by the person with MND or their family carer as soon as diagnosis is received. This is up to £500 and can be used to help with the cost that services charge to create the synthetic voice.

At present, there is a pilot running for our voice bank volunteers. This project is trying a new volunteer role predictively called, *"The Voice Banking Volunteers"*. They will support the person living with MND in the short-term through the voice banking process, and when it is complete they hand over or back to the person's speech and language therapist. We hope this will save time for the speech and language therapist. Seven areas are involved in this first stage:

1. Cornwall and Devon
2. South Central, which is Portsmouth and Hampshire
3. Northwest London
4. Thames Valley, which covers Oxfordshire and Berkshire
5. Central Midlands, which is Buckinghamshire and Bedfordshire
6. West Yorkshire
7. North Wales

I list these because we are looking for people with MND support on this so if you have someone you think would be suitable, please do refer them. The link for the form is on the slide.

This project will be evaluated between October and December this year and a national rollout considered, based on its findings. In addition to these services, support grants can be offered to help people with the purchase of tablets or apps. This does need a referral by health and social care professionals, so let's have a look at these next.

In terms of grants, the Association can offer some financial support to people living with MND and their families. There are currently four types available, and you can find them all on the Association's website along with the application forms for them. MND is a very good place to start as they can advise or put you through to further help if necessary.

The Support Grant – this is available to anyone living with MND and awards of up to £1,500 can be made. We may, on occasion, be able to offer more, but this would always be treated as an exception. This type of grant may be used if the equipment a person in your care needs is not available from statutory services. You will need to apply for this type of grant on their behalf. An assessment of need is required, and all statutory funding options must have been explored.

The Quality of Life Grant – this type of grant can be made up to a maximum of £1,000 and are available to anyone living with MND. No assessment is required, and application can be made by anyone, so a family member, Association Visitor, health and social care professional or a Regional Care Development Advisor. Some examples of grants that have been made include money towards a holiday, a mobility scooter, hairdressing, a computer and a cleaner to help with household chores.

The Carer's Grant is open to unpaid carers aged 19 or over caring for someone with MND. An application can be made, again, by any family member. The aim of the grant is to allow the main unpaid carer to take a break from their care and duties. Grants can be made up to £500 and things which qualify may include a pamper day, a short break or continuing or even starting a hobby.

The Young Person's Grant predictably is open to young people aged 18 or under, who are affected by MND. Again, an application for up to £250 can be made by anyone. The aim of these grants is to support purchases of anything that might help the young people in the family in their day-to-day life

or protect their mental health. Things which have been improved include contribution to buying a laptop, a trip to a falconry centre and even a drum kit.

We can also support you with opportunities to increase your knowledge. Master classes are currently run throughout the year on one theme. They are delivered in different locations, are usually day events. During 2018, master classes are focusing on respiratory support for people living with MND, and I'll keep you posted if anything comes up for speech and language therapists.

Special interest groups are a resource and support to health and social care professionals. They may be small, locally based groups or larger and more regionally focused. The purpose of them is to promote and share good practice, bring together professionals to increase mutual understanding of roles and develop problem solving approaches to the treatment of people living with MND. To find out what's going on in your local area, contact your RCDA. You can find the contact details on the website in the 'Getting Help' section.

Through the partnership between the College and the Association, I'm happy to hear other ways in which you feel we might support you in your profession.

Finally, the Association monitors the experience of people living with MND through an annual survey. RCDAs, which we like to think of as our eyes on the ground, report back on local issues. The Association considers what action might be taken for these issues which may result in developing a campaign.

In terms of campaigns, we campaign at a national level. For the 2015 General Election, our manifesto and campaign were to improve access to communication equipment for people with MND. Thousands of supporters emailed or met with their parliamentary candidates, urging them to take action. As a result of the campaign, NHS England made a commitment to re-double their efforts and issued unreserved apologies to people with MND for the problems they had faced in accessing communication equipment. We have since seen an improvement in access of people living with MND. Our current campaign is around benefits.

The Association also aims to help where it can with local issues. To help, we need evidence of a problem. Your local RCDA can flag a situation that they feel might benefit from the help of our campaigns team. I would encourage you to talk to your local RCDA about any negative trends, poor care or missing services you are aware of for people living with MND or their carers. The kinds of questions that are useful for you to consider are:

- What is the issue?
- How long has it been going on?
- How is it affecting people living with MND?
- How many are affected?
- What is the solution that we want?
- What have we done so far?

The association is keen to help you and your patient, so please do link with us.

Thanks for listening.

Claire Moser, Policy Adviser, RCSLT

Thank you very much indeed to Jennifer and Steven. I think you all agree that those were absolutely fascinating presentations. Just to remind everyone that all the presentations will be online very soon. We have received lots of questions, so I'm going to kick off immediately.

We've had a couple of questions which are for you, Jennifer, when you spoke about statutory services, and we've asked for clarification if this refers to social services or local community SLT services? A couple of people just wanted you to clarify what the phrase "*statutory service*" referred to.

Jennifer Bedford, Head of Partnerships, Motor Neurone Disease Association

We were talking there about statutory services that are provided through social services, so it might be things like a ramp that needs to go in, or adaptations to the home, that kind of stuff.

Claire Moser, Policy Adviser, RCSLT

That's brilliant, thank you very much indeed. We've received quite a few questions around AAC. So, I'm going to direct these towards you Steven, if that's okay? Lots of different questions around access, equipment, and how to discuss it with the patient. Do you have anywhere you could signpost people to, to get more information?

Steven Bloch, Senior Lecturer in Acquired Communication Disorders, University College London

Yes, well, there's a number of sources of information. As I said, a few years ago myself and a team of very wise clinicians and technologists from around the country put together, I think, some excellent resources which are now available for professionals on the MND Association website. I think they are titled, 'Best Practice Guidelines for Augmented and Alternative Communication'.

I think there are a couple of key messages about AAC. The first is that we... and this may sound very simplistic, but the most important thing is the person, rather than the technology. It's their communication that matters and the technology needs to support them and what they need to do, and sometimes there's a tendency to become quite obsessed with the technologies and seeing how it can work with the person. My philosophy has always been that the technology will always change. There will always be new devices available and new modes of access, but underneath that the people themselves are always there, and they will be experiencing communication difficulties. So, we've kind of got a head start with that and the more preparatory work we can do with augmented communication, the easier it will be for us all to work together.

I'm deviating slightly from this question, but I will get back to it and to say that early intervention is, where possible, a good thing. I think, the trick is to make sure that that early intervention is appropriate for the person with whom we're working. So, it's not the case that one just goes in like a bull in a china shop and says, "Right, let's talk about communication aids". It's very much about establishing what that person needs to know at that particular point and as they progress their knowledge and earn a confidence in managing their own knowledge and their own symptoms, then I think the therapist's job is to introduce them to the range of options that are available ahead of when they may be needed so that the decision making process can be fair.

In terms of getting hold of that information, and this is where I come back to the question, I mentioned the hubs, they are incredibly useful resources for information and advice. I mentioned Richard's work with the voice banking, and I referenced Helen Patterson at Putney whom I know does excellent work, and the team up at Sheffield as well. In fact, all of the hubs around the country are there to support clinicians in making decisions, and I don't think there's ever a problem in ringing up a hub and just talking through cases or talking through ideas, so that you feel confident. I think a lot of the work in AAC is about confidence – confidence in your own skills and not being overwhelmed by the sense that somehow, out there, there is a machine that will resolve everything. Technology can support occasionally, but it certainly can't replace.

Claire Moser, Policy Adviser, RCSLT

That's great, Steven. Thank you very much indeed.

We've received a few questions in around carers, which is very interesting, talking about how we can support carers better and thinking about social isolation. And, I was wondering, Jennifer, if there's anything that you could suggest which might help if we've got people out there who have got a partner or family member who's got MND, any support that we could offer to the carer themselves?

Jennifer Bedford, Head of Partnerships, Motor Neurone Disease Association

Yeah, thanks for that. I mentioned the branches and groups that are around the country, so there is a resource there where people can go and meet people that are in the same situation as themselves.

So, a lot of people do find that support, and they meet in a range of different places, from garden centres to peoples' houses as well. What I would recommend is have a look on the website, and you'll find whether there's a branch and group in your area to actually meet up and deal with that social isolation thing.

We are very aware of the issues that the carers do suffer when they're looking after a whole family as well as somebody living with MND too. As we are part of the Carers UK Carers Week, which is coming up next week actually, and so we're pleased that a carers action plan has just been launched today. So, we're going to see what's in that and hopefully, some of the stuff that we've asked for to deal with people keeping themselves healthy and well when they're carers is really important. So, if you want more information about what sort of things that carers are up against, that's a really good resource to have a look at. There's just been a survey that they've done as part of that which is a good place to find out about things.

Claire Moser, Policy Adviser, RCLT

That's great, thank you very much indeed. I've received two questions coming in around voice banking, a lot of interest in it around access and when people can't access it. So, a specific question around the needs of the person and when they can't access voice banking. Can our speakers say anything further around this please?

Steven Bloch, Senior Lecturer in Acquired Communication Disorders, University College London

Okay, so Jenny and I looked at each other saying, "Who's going to deal with this one?" I'll go first.

I think the MNDA is really ahead of the field on this in being very keen to set up resources to support voice banking. And, as I mentioned, Richard Cave's work, again he's at Putney but working with the Support of Motor Neurone Disease Association to find out what it is that people need from voice banking, what are their experiences of voice banking? I know he's particularly interested in people as well that may not want it and why they may not want it. So, it's not just the case that everyone should have it, but the question specifically is about the people that want to get access to it and can't.

My sense is that, at the moment, it is very much about contacting the MND Association as soon as possible, so that they can be put in contact with Richard and the volunteers that he is working with to support the process of voice banking. Perhaps, I can just say something about this because this speaks to something quite important about technology overall, and that's that the box that you get, or the software, or the app, is all very well and good, and it all seems very familiar to us because we're all using tablets and smartphones, and all the rest of it. But, something like voice banking is a complex process. It is not as straightforward as it appears.

Richard's project with the MNDA is very much looking at, "How can people be supported in the process of doing voice banking?", and that's deciding whether it's right for them as well as the actual technical process. So, it perhaps suggests that if people are having problems accessing it, that's because this is a fairly new emerging technology. I know it's been around for a while but in terms of building it into the infrastructure of people with MND's experience, we're now seeing it bedding down. In the past, it may well have been that people hadn't had access to it, just as they never used to have access to some of the newer technologies like Eye Gaze and even some of the more basic voice app communication systems. But now, our expectation is that everybody that wants it should have access to it.

So, the question is, for therapists, get in there as quickly as you can without jeopardising your relationship with your client and obviously making a blunder, in terms of promoting something that may not actually be needed or wanted. So, again, it comes from the judgement of the clinician about when to introduce this stuff, but I think there's a reasonable consensus here that the earlier the better with sensitivity.

Claire Moser, Policy Adviser, RCSLT

Thank you, that's great Steven. A question that's come in for you Jenny, there's been some interest in the voice bank volunteer pilot scheme. People are asking, "Does the therapist need to be involved? Does the family need to be involved, or what is the route in which people can apply?" Could you provide a bit more information please?

Jennifer Bedford, Head of Partnerships, Motor Neurone Disease Association

I certainly can. It would obviously need to be... the patient would need to want to be doing it in the first place. I think that's the thing. I don't think a therapist would even think about referring someone without making sure they'd checked it out with the family in the first place. So, it would be a combination of those things, but it is the actual speech and language therapist that makes the application to be part of the project. So, it would be a collaborative thing between patient and therapist if that's what's for them, and then go to the link that I gave on the slide, and the application form will be there. If you have any other questions as well, contact the chap that Steven's referred to.

Claire Moser, Policy Adviser, RCSLT

Thank you, Jennifer, that's great. I've had a question just come in around alternative feeding, and "When should a therapist discuss this with a patient? Is there an appropriate time?" I'll look to Steven, is there any advice you could provide please?

Steven Bloch, Senior Lecturer in Acquired Communication Disorders, University College London

I think, again, the message here is sensitivity, but it's also realism. When I was talking about, very briefly... I mean, I had to go through those slides at quite a pace. I did mention, obviously, non-oral feeding and PEG Management, and the evidence is, I wouldn't go as far as saying it's controversial, but I'd certainly say there are differences of opinion around the country, in fact around the world, about the timing of these things in terms of procedures. But, I think the Sheffield MND Care and Research Centre research project, which is called 'ProGas Study Group', from 2015, certainly found that the greater the percentage of weight loss from diagnosis to gastrostomy, the less likely it was for patients to recover this loss.

The evidence that we have suggests that if people lose more than 10% of their weight from diagnosis, as a result of MND, they're much less likely to do well with a gastrostomy. If we put that into a kind of clinical context, and certainly from neurologists' kind of thinking, the census there is that it's better to form a gastrostomy procedure earlier than it is to leave it later and later and later. The more someone's weight deteriorates, the less likely they are to benefit from the procedure, however it's not as simple as "everyone just has to follow this rule". The whole point here is about individualised care, and it's certainly not the speech and language therapist's decision alone. It's part of a team decision.

So, my personal view here is that, early discussions around sensitive topics is always better, but for that to happen you have to have the right relationship with your patient and with their families. I mentioned earlier about building rapport and building a relationship, and it's the same for AAC, it's the same for advanced care planning, it's the same for legacy work. All of these things are delicate, and they involve emotional risk. And, I think that for us, it's speech and language therapists in particular. I know there are some other professionals here and it applies to everyone. I'd say that the skill of the clinician here, and it is a skill I think that speech and language therapists in particular do have, is one of building a relationship with someone in order to prepare them for some of these things.

In terms of how one does that, I think it's a very neat process of establishing what information they know, what their experiences and expectations are and dealing with things in a step-by-step basis so that you're not just jumping in with information, even though you think that that's maybe what they need at that particular point. You're sensitively judging the moment and reaching a point where you may sensitively say to someone, "Would you like to know any more about the options you have to support your feeding and swallowing, both now and maybe in two or three months' time?" so that you are giving people constantly the choice for the types of information that you may want.

But, I do think, again, that speech and language therapists in particular have a really key role in spending time with people and building that relationship. Because communication is what we really are all about. That sits at the bottom of so many of the issues that people with MND experience – breakdowns in communication but also an inability to access the information that they want when they want it. So, again, I'm sorry, this opens up quite a complex area for discussion about exactly when you do certain things. I think early is better but, again, it's all about sensitivity to the individual client that you have in front of you at that particular time.

Claire Moser, Policy Adviser, RCSLT

That's great Steven, thank you very much. Just to remind everyone who may not have had their questions answered today, please don't worry. We will put answers online, so do keep your eyes out for those. Just to let you know, we've got a couple of minutes left of questions, so I'm going to ask Steven and Jennifer if they would like to highlight what their favourite resources are.

Jennifer Bedford, Head of Partnerships, Motor Neurone Disease Association

I think, from the Association's point of view, one that's won an award is, I mentioned earlier, the End of Life Guide, and that is good. It does take people through, at their own pace, what's going to happen at that end of life. It is important, I think, to highlight that one for people.

Steven Bloch, Senior Lecturer in Acquired Communication Disorders, University College London

Where do I begin? There's so many things. Right, my favourite resources... I mentioned digital legacies, and I think that this is something that I'm becoming much more excited about for a number of reasons. I think one of them is the therapeutic benefit. We haven't spoken a lot about AAC, but one of my most rewarding experiences in working with people with MND has been that partnership.

I think that something like digital legacies and advanced planning and legacy work, life histories, recording stories, there's something here about using people's own experiences and their expertise. So, there may be something here that's very important to me which is about recognising that people with MND and their families are experts in their own conditions. They're experts in their own lives, and we are there to support them with our own experiences and knowledge. But, they are the ones who should be in control as much as possible. I think some of this planning work, like digital legacies, gives people more control and perhaps, that's one therapeutic benefit of this type of work – where people can have some say in what is, as we know, a horrible condition that affects everybody, professionals as well as carers and people with MND.

So, anything that allows us to work together and share ideas, for me, is a good resource.

Claire Moser, Policy Adviser, RCSLT

Thank you very much. Well, I'm going to have to draw this webinar to a close now. I would like to thank Steven Bloch and Jennifer Bedford for their excellent presentations. Just to let you know, they will be online. Please do continue using the two Twitter hashtags – #rcsltwebinar and #motorneuronedisease – to continue the conversation. And, don't forget please that your feedback is very welcome so when the survey pops up on your screen, please do post any comments that you have for us.

I'd like to thank everyone. And goodbye.