

Coronavirus and MND Ask the Experts 11/05/2020

This content provides the main points from a live interview held on 3 April 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 Director of Care Improvement at the MND Association. During these worrying and uncertain times for everyone, we decided to engage with our wonderful health care professionals, supporting people with MND across the country. You may have seen the first two Ask the Expert videos with clinical advice from leading neurologists across the country. I hope you found those videos useful – if you haven't seen them, please do take a look in the Coronavirus hub on our website.

For our third video today, we thought we would utilise the experience of our clinical teams across the care centre network, working front line to support people with MND. We are joined today by three of our brilliant colleagues, many of you will know or have met them.

First, Jan Clarke, Consultant MND Nurse at the National Hospital for Neurology in Neurosurgery, at the National Hospital in London. Jan is also the key co-ordinator for our care centre there. Next, Pauline Callagher, Lead MND Specialist Nurse and Co-ordinator at the Preston MND Care Centre and thirdly Tracy Thomas, Lead Clinical Nurse and Care Network Co-ordinator at the Peninsular MND Care Centre Network in the south west of England

Thank you for joining us here today. I think we've got a really good opportunity to look at the provision of care across the country and through the different care centre network models you represent. I'm looking forward to the discussions and we'll go through some of the questions that have come up.

Question 1: What have people in your area been contacting you about most during the lockdown?

Tracey:

I think it was really surprising. I don't think we were prepared for how busy the phones were going to be for those first few weeks, after lockdown happened. The main thing that we had to put up with was the mixed messages from government, around who was a vulnerable person or extremely vulnerable person, and who should be shielded. So many calls from people saying 'Where's my letter from the government, I think I should be shielded.' so there was a lot of work that went into trying to sort things like that out for people. We're very lucky down here because we managed to work very closely with the commissioners and in the end, virtually all our MND patients were put onto that list so we've not had to worry about that since, but that was the biggest thing I think that we had to deal with. But also lots of really simple things, like 'How do I get shopping if I can't go out? How do I get my bloods checked?' and things like that. But I think the hardest thing was a lot of patients asking the question 'What happens if I get Covid 19?' and so there were a lot of talks about would you want to be hospitalised, what would your choice be? That was quite a hard bit of the initial few weeks.

Jan:

I think that's pretty much echoed across London as well. I think we were amazed by how many non-MND questions we got for the first 2 weeks – it was all about 'Why aren't we on the shielding list, and where's our letter?' We were very lucky that we could turn that around and put everyone onto NHS digital. We put our entire database on as quickly as we could, so that these patients could be shielded. But most of it was about accessing services if they were to stay home. I think we were surprised by the lack of MND specific questions to start with and then they started coming, and then they came in their hundreds. What if? When? How? It was a very unusual time because you're not prepared yourself for the situation, let alone to support people that are ill. It was a very difficult time trying to find information, because of the governments ambiguity over some things really.

Pauline:

That was the same for us really. Lots of questions about whether or not they could access care agencies in the normal way – 'Were they safe? Would they have the correct PPE?' That kind of thing, along with the issues about shielding and the other things that have already been mentioned, were echoed in the north of England as well.

Question 2: What has changed most for you and your team during the current period?

Jan:

I guess in some ways, we're now working as much as possible remotely, so we can social distance amongst our colleagues and keep everyone well and still working. That's not something we've done before. We've moved all of our consultations to

telephone or skype consultations, which we've been trying to do previously, but I suppose had been slow to adapt to that. Then we adapted overnight into doing that. All of our consultants are now contactable by phone and we've set up every patient to be able to contact them, and so that's a good thing. I think that was probably the biggest change for us.

Tracey:

We decided at the beginning, with my colleagues Jenny and Natasha, that we would open a seven day service. We changed our opening hours, so that we worked from 8am to 6pm every day and 11am to 3pm at weekends, because we were very nervous about what might happen to people at weekends if there were problems. That was the main thing we did.

Pauline:

That was similar to us really. We ended up working over the Easter bank holiday because it was very busy with telephone calls, where we wouldn't normally. We've been working from home for the most part.

Question 3: Where have your teams been based during lockdown?

Pauline:

We've got quite a number of people in our team that are part-time and we've tried to limit the amount of people in the office at any one time, so the office is always covered. People can ring on the normal telephone number, just as they can get access to the normal email address. But because we're working from home as well, we've all got mobile telephone numbers, so we can access our own patients and video call them from home. It's been set up securely, so we're able to do these things from our own homes, using the Secure Health Records Network. It's been a very different but productive time and we've been able to continue to provide quite a good service.

Tracey:

We are strategically a community based service anyway. Although we have an office in the hospital, right now it's in the middle of the red zone [where the virus may be treated] so our office is completely out of bounds. We are all working from home, but have laptops, mobiles and access to video conferencing, so like everyone else we've been managing from home quite successfully.

Jan:

I think for us we're very lucky. We didn't think so a year ago, when our hospital went completely digital, but actually we're quite grateful of it now, because we can access everything from home. You can still look up lab results, you can still look up patient records and that's been quite a gift. That would have been quite difficult to do if we hadn't got to that point before April.

Question 4: Within the MND Association, when the crisis started, we were very worried that healthcare professionals who normally support people with MND would be redeployed – and therefore not able to support people with MND across the country. So we are interested to hear if you've seen redeployment of staff?

Tracey:

We were really surprised how quickly people were redeployed out of their normal roles. For example, our respiratory teams were whisked off to intensive care, a lot of our occupational therapists and physiotherapists went into acute discharge teams and things like that. And I guess for us, that was partly the reason we decided to work more – because patients were losing that contact with their local team. That was causing quite a lot of concern, so at least if they could ring us, we could help them access the support they needed. There was always somebody available from every team, it was just a case of getting to know how to navigate to them really.

Jan:

I think that's much the same for us really although my background is in Intensive Therapy Unit (ITU) so I've been redeployed to ITU for two long days a week during the crisis. One of our other MND team members is an ex-ITU Nurse as well, so he's been there too. But we have always managed to keep someone available here every day, so we've been very lucky. But I think the other support services – our gastro team and our radiology team – all those doctors were redeployed to Covid wards. Because of the medical skills they needed, rather than their speciality. And our respiratory teams of course all went to ITU. Our hospital took a huge amount of people with Covid, in fact our main tower of the hospital all became Covid activity and all of our elective surgery and elective work stopped. I have been really amazed at how adaptive everybody is to do that, but also how willing people are to still have those conversations on the side, 'Can I just ask you about an MND patient? What could we do?' The generosity of spirit has been amazing, not just in the MND team, but in the wider team as well, so that's been a really good thing.

Pauline:

Absolutely, I would agree with that. We haven't been redeployed from our service within the MND team and we've been able to continue at the moment. We have taken on some additional roles, which has been fine. Because we're not going out as much, the spare travel time not visiting patients has allowed us to do other things, to help other teams out. Some of our other healthcare workers, such as physiotherapists and occupational therapists like you said, have had to move onto other roles, but the service has been able to continue in much the same way. We have been able to provide the same kind of support that we would have before.

Question 5: If someone with MND had their healthcare professional redeployed, how would they go about getting their care?

Jan:

I think because we have always managed to keep the team running, that's not been an issue. The person with MND wouldn't have known that logistically things have been slightly more complex for us, so they have still been able to get their care. Our biggest problem has been that elective work stopped, so our ability to admit people for PEGS or RIGS [tube feeding fittings] had to stop. Actually, that was the right thing to do at the time, because hospitals were unsafe for that person to come into. If that surgery was not absolutely urgent, then they were safer being shielded at home. That's been the same for our NIV service as well. The really nice thing is we did our first PEG last week and our NIV has restarted on a slow basis – we have to have everybody rapid tested for a Covid test first before we can admit them but we are now restarting those services. I think that was the hardest thing – putting things on pause and just hoping you could restart it just quick enough where nobody really noticed the pause. It's good news that it's all back up and running now.

Question 6: Regarding non-invasive ventilation (NIV) and feeding tubes, are they still available during the lockdown?

Tracey:

Interestingly in the south west, most of our NIV is set up at home, so people haven't had to come into hospital. We managed to set up NIV for one person, who needed it urgently, but actually we've been really lucky that no one else has urgently needed it. We're now sort of back to fully normal for lung physiology being done at home as well, so that's all restarted again this week and we haven't had any problems with ventilation. PEGS for tube feeding have been a little more tricky. At the beginning of this, we had to cancel three elective PEGS, but two of those have been done this week after rapid Covid testing. It's meant a little more negotiation. It's been an undercurrent with all our patients that if something was needed urgently, that we would find a way to do it, so we have been very lucky.

Pauline:

That's been the same for us too. It's difficult to organise these things, because you do tend to bring people into hospital for them and that is more risky at the moment. We've started doing more non-invasive ventilation in the community to try and protect people. Obviously, they have to come in for the feeding tube placement, so that does take longer to organise, in order to protect the patient.

Question 7: As many people have utilised technology during this period, how have you been embracing technology to help support people with MND?

Tracey:

Embrace might be too keen a word! But yes, even I have been trying my best. We have been using Microsoft Teams for team meetings we also have a system called Attend Anywhere, so we've actually run an MDT clinic with a neurologist, myself and a respiratory physio. That was our first one and it went brilliantly, and in the next couple of weeks we are doing our first MDT meeting with the community team all present on Teams. That may be quite riotous I suspect, but yes, we are using it and getting to grips with it slowly.

Jan:

I think one of the things it showed us, is that there's so much more you can do that we've not really considered. Trying to get Skype in for general appointments in the hospital has been a difficult thing, just because of the way things are funded, the encryption needed and things like that. Actually we managed to move overnight to do these things, as it was the only way to hold the service. And now the great thing is there are team meetings, and MDT's across the whole of London. We attend some of them, because they are in our vicinity to reach, but we now attend almost all of them via Microsoft Teams. That's been an absolute gift, because they are the people working on the very front line, going into people's homes. Being able to hold MDTs about individual patients following that, I think it will change things about how we work in the future, and be more accessible to more people. That's a really good thing from a professional point of view, but I think for patients as well. There were always those patients who, when they got so poorly, that travel to a clinic became too burdensome to want to do (and that's understandable). But with Skype now, that you can still connect with that team you've known throughout your whole journey and still keep that going, that's really powerful. And I think definitely something we're going to keep working with.

Pauline:

Absolutely, because we cover a large area in Lancashire and South Cumbria, as well having the ability to attend a clinic appointment in Barrow when a patient's newly diagnosed, which we wouldn't normally be able to do. It's been a real godsend and cut out a three hour journey for us to go and see a patient, when we're not actually having to do a physical test on them. It will be a really good thing that we've been able to adapt to use this technology.

Question 8: My last question was about whether you feel you will use those innovations and technology in the future, and I think you have all answered that question with a yes.

Tracey:

I think it is yes. I would just slightly interject that for us, when someone's newly diagnosed, we tend to see them at home as a first visit. And I don't think that's something we will stop, mainly because once you've got the layout of someone's home, you know what their access and their stairs are like. For us as a service, we wouldn't want to stop that, but certainly for follow up visits, yes it will be very useful.

Nick:

it just leaves me to say thank you for your answers today. It's been really insightful and a really good opportunity to understand what's happening up and down the country. Thank you for your time today. My colleagues in the care team will bring together all the key points and communicate them through the MND website, so please do take a look over the coming days. We have a specific Coronavirus hub on the website, so please do take a look at that and access everything you would like to about MND and Coronavirus. Any questions you've got can be accessed through that hub, but please also take the time if you wish to speak to our staff through the MND Connect helpline which is 0808 8026262. Please take care out there and thank you for everything you are doing in supporting people with MND on the frontline. It's much appreciated by us all, so thank you very much.