

Coronavirus and MND Ask the Experts 03/04/2020

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

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 this worrying and uncertain time for everybody, we're receiving a lot of questions at the MND Association, especially through our MND Connect helpline and our regional teams. Some of which need clinical and expert answers and we've formed an expert panel to help us.

We thought it would be really useful to broadcast some of the guidance and thoughts from the group to you. So we're going to give this a go and have set up the technology. It's my hope that we can repeat this and maybe invite different guests as we progress through the weeks.

I'm joined today by 3 of our brilliant colleagues who many of you will know:

- Professor Ammar Al-Chalabi, Professor of Neurology and Complex Disease Genetics and Director of Kings MND Care and Research Centre.
- Professor Chris McDermott, Professor of Translational Neurology and Consultant Neurologist at Sheffield Institute of Translational Neuroscience.
- Professor Martin Turner, Professor of Clinical Neurology and Neuroscience and Director of the Oxford MND Care and Research Centre.

Thank you for joining us today.

The questions that we received have been passed onto you all and are in no particular order. We are going to try and work our way through them. They will of course remain anonymous.

So, let's see how many we can get through in about twenty minutes and any that we don't get to, we can answer next week.

Question 1: Is it still safe to take riluzole with MND during the coronavirus outbreak?

Ammar:

Thank you Nick. It depends on how long you've been taking it. The difficulty with riluzole is that some people in the first 3 months or so develop a reaction either in their liver or in their blood. It's very rare, but it's important that we check for that. And that's done with blood tests, checked monthly for the first three months, then 3-monthly for the rest of the year. So, if you haven't started riluzole yet or in the first three months of taking it, it may be difficult for your GP to take your blood at the moment. Not definitely, but probably. In which case, you may decide not to start taking it or to stop taking it for the time being. We don't know how long this lockdown will last, but if you're outside that three-month window, your bloods will have been taken every three months or so anyway. This means you can probably carry on taking riluzole for the time being. But, if you wanted to stop it, that would also be fine to do for the time being. If you've been on it for more than a year then your blood tests will be known to be stable, otherwise you wouldn't be on it for that time – so you can carry on taking it safely.

Question 2: Does the use of non-invasive ventilation increase the risk of spreading the coronavirus?

Martin:

Using NIV does increase droplets in the atmosphere and so there is a concern if someone has an established infection. It risks infecting the people who care for them and are around them. I think sensible precautions are to try and limit the use of NIV ideally to one room, or as few rooms as possible when someone has a confirmed infection. If they don't have an infection, it's fine. Generally care workers will be taking sensible precautions. If they are coming in externally, they'll be using appropriate protection and obviously family members are thinking about that. If they've got symptoms then they're not to go out and just be aware really that they may be at risk of getting the virus if the person with MND has the infection. It's a sort of a practical issue, but we also need to think about simple things like coughing as well as more sophisticated things like NIV.

Question 3: Following on from that, are there any extra hygiene measures that people living with MND could take during the coronavirus outbreak?

Chris:

As Martin said, the most important thing is to take sensible precautions regarding hygiene. Those with motor neurone disease who are more vulnerable, in particular with respiratory problems, may want to isolate themselves. Also, when people are interacting with them, to make sure that recommended hygiene measures have been

taken. This means paying particular attention to hand washing when carers come into the home and when carers leave, and wiping down anything that's been brought into the household. Just being sensible really.

Question 4: This next question is open to all of you in turn. What are your thoughts regarding the impact that the COVID-19 crisis is having on the provision of care for people living with MND?

Ammar:

It's a big question. The main issue is that people can't come into clinics anymore. These now have to be done remotely, for the safety of the person being seen, their carers and also for the staff. Most centres are able to offer video or telephone consultations, but the problem is for aspects of care such as physiotherapy or occupational therapy, where input becomes more difficult. But it may be possible to provide these in the community. Any difficulty with examining somebody, particularly if it's their first diagnosis, is to some extent reduced with examination by video. We obviously won't have the hands-on aspect, so some parts of the examination we can't do. But in medicine, most of the diagnosis doesn't come from examination, it comes from the story that the person tells us. So to a large extent, from the diagnostic point of view things would be okay, but it'll be more difficult to get investigations done at the moment. For those already diagnosed, ongoing care should be possible in most cases. If someone needs a new intervention like non-invasive ventilation or a gastrostomy, that would be much more difficult to achieve in the current climate. It won't be impossible, but will just take a lot more logistics locally to achieve it. To summarise, care should be able to continue, just more difficult. But we can mitigate most of the problems of not seeing someone in person.

Martin:

I think at the moment with the increase in testing over the coming month and into May, we'll start to see the establishment of clean areas in hospitals to a larger extent. That will allow us to plan procedures such as gastrostomy or for the initiation of NIV, but right now it's very much emergency mode. There's an enormous amount we can do over the phone, talking to community teams and new solutions for more tricky problems over the coming months.

Chris:

I'd echo what Martin and Ammar have said. Teams are thinking creatively about how we keep in touch with our patients, using telephone and video consultations. I think the Motor Neurone Disease Association has been providing lots of up-to-date information to support patients – and initiatives like this, to get information out to patients, to explain what the COVID-19 crisis means to them, is also very helpful.

Question 5: We mentioned gastrostomy there. Does having a gastrostomy and then contracting COVID-19 create additional issues for people living with MND?

Martin:

In general people who have a gastrostomy will be managing that. Some of them will be doing it themselves because they have the dexterity to do that and that's much easier. Having an infection doesn't create a particular issue there. If the gastrostomy is being managed by someone else, then if the person with the gastrostomy has an infection, more barrier methods need to be considered than normal – for example, wearing gloves and basic hand washing. So overall it doesn't really change things and tube feeding is useful to keep nutrition levels up if someone feels a bit under the weather.

Question 6: At what point during the virus infection is it recommended to ask for external help? In other words, how do you know when symptoms have become high risk, as opposed to just being unpleasant?

Chris:

That depends on where somebody is, in the journey with MND. If someone is very early on, just after being diagnosed, or perhaps just has a weak hand or weak arm, then the current government advice applies – to use the NHS 111 helpline to seek information online or by telephone. They can seek more urgent support or face-to-face medical intervention if they begin to feel more breathless, or new breathlessness. For someone with more advanced motor neurone disease, who is perhaps already breathless or using non-invasive ventilation, then getting new symptoms or if the breathless feeling gets worse, that should trigger contact with emergency services.

Question 7: If I'm taken into hospital with coronavirus and MND, what treatment would I be given – particularly if ventilation to assist with virus symptoms is not available to me?

Ammar:

There are still a number of steps that can be taken. Most people would be assessed and, if appropriate, given oxygen. This is because people are usually taken into hospital due to chest infection, with a viral infection or a bacterial component. With bacteria, they'll give the person antibiotics. Some people who are not responding, even to oxygen, will be given non-invasive ventilation with oxygen. That uses a different type of machine to those people with MND normally have for non-invasive ventilation, as it allows oxygen to be given as well. And in many cases people will be nursed in a prone position on their front or sitting up. These positions allow the

diaphragm to move more easily and more of the lungs to fill with oxygen (where the blood is) which seems to improve oxygenation generally.

Question 8: Is upright positioning in a chair or bed helpful for people with severe virus symptoms such as coughing or breathlessness?

Ammar:

I think the answer would be yes to that.

Question 9: A difficult question, but will my carer or immediate family be allowed to visit or support me if I'm taken into hospital at the moment, whether for virus symptoms or other urgent treatment?

Martin:

I think we have to meet this one head on. It is a difficult answer and it's no. Certainly for April, and possibly significantly into May, it won't be possible to have people visit you in hospital, or even to go with you.

Note: Please check with your local hospital as NHS Trusts may have differing policies depending on circumstances, and approaches may continue to change.

Martin:

Each person may need to factor that into their decision making. For some people, they need to weigh that up. What we're hearing from paramedics is for people to ensure they take into hospital a phone with a good supply of data, and their phone charger. That way, they can stay in touch with family while on the. There would be no issue or difficulty with using a phone in that way. I think people have to assume that if they are going into hospital that it will be alone.

Question 10: How long are you likely to remain in hospital if you recover from severe virus symptoms? Is there an anticipated period of admission, or does it vary widely depending on how well each individual responds?

Chris:

It will vary depending on the individual's circumstances. The desire is to minimise admissions as much as possible, so the first question will be 'Can this patient be managed at home safely?' This might be with using NIV a little more, or with oxygen if oxygen is proven to be safe. We have to be careful using oxygen with MND, but it can be used safely with the right controls. If patients do need to be admitted, we will try to quickly manage things with all the steps that Ammar mentioned – for example, with antibiotics if there bacteria seem to be involved in the infection. As soon as

someone is comfortable and recovery is moving in the right direction, I think people will be released from hospital as quickly as possible. That will be the same for patients with motor neurone disease as for other conditions or people that were previously healthy. Hospital staff will want to minimise the stay in hospital.

Question 11: What treatments or remedies can be given at home for virus symptoms, other than paracetamol for fever?

Ammar:

I think that would be the same for any type of cold or flu symptoms. Definitely a lot of rest and sleep, as far as possible. Nasal decongestants may well be helpful, also things like Vicks or other eucalyptus-based treatments, over an inhalation of warm air. Menthol based treatments and things for a sore throat may help, and people need to remain very well-hydrated of course. All of those things seem to be helpful at home, but there's no specific other treatment. It's controversial over whether drugs in a group called nonsteroidal anti-inflammatory drugs, like Neurofen or Ibuprofen, should or shouldn't be given – nobody really knows. But current advice is to take paracetamol as the main support to lower temperature and making yourself feel better.

Question 12: If you're recovering from coronavirus, are you automatically immune or could you get infected again?

Chris:

There are two issues here. Somebody who has a coronavirus infection is at risk of getting secondary infections with bacteria. This will be treated with antibiotics, so that's one aspect. The other thing is whether having had coronavirus, are you then immune or could you catch coronavirus again? The fact is, we don't know, as it's not been proven – but we assume you would be immune and unlikely to get coronavirus again. There are going to be tests, looking at peoples immunity to coronavirus, but they've not been worked up properly yet and probably not likely to be available for a month or two. Once we have those tests, we'll begin to develop evidence about what immunity actually looks like in the population. Our gut feeling is yes, you probably won't get re-infected with coronavirus, but we don't know for certain yet. The evidence isn't there.

Martin:

Can I just add a point on that? One of the issues about immunity is that even if its only for a relatively short period of time, you allow time for the virus to disappear from the population. That's the key thing really. It's not necessary for everyone to become immune as such, but if you create a 'firewall' so nobody's catching it, the virus usually disappears. We're used to situations annually with influenza, where each year there's a new strain, and that's actually more of an ongoing public health issue really. But hopefully in this situation, COVID-19 becomes history or is compressed into a situation where it can be managed on a very, very low case-by-

case basis. I don't think people need to be concerned about lifelong immunity or that this set of circumstances will be forever.

Ammar:

And I would add as well, that there have been no properly documented cases of re-infection. So it looks like people probably will be immune, although as Chris said, we don't really know. There are different strains of coronavirus, but they seem to be geographically limited to a large extent. That means if immunity to one strain works as it does for influenza, then probably (but not definitely), people would be immune for some time.

Question 13: Following discussion about the Government's extremely vulnerable list, to help with priority access to local services, would being registered as such impact on access to treatment in hospital?

Martin:

Classification as extremely vulnerable is very helpful and I have seen first hand where it has helped local authorities identify people who need support, food and deliveries. There are extremely robust processes in hospitals, that existed long before COVID-19, to support anyone admitted with a very serious condition, like MND. With anyone seriously ill, we always want to have a conversation with that individual, about how far they want to escalate interventions. Part of that discussion is someone asking us, 'Well, what are the chances that intervention at that level would benefit me? Would I get back to the status that I had before I was seriously ill?' That's a very individual thing, but we have experience with people in various states of advancements, across all sorts of conditions. So those conversations will still happen of course, and where someone is very ill, they may need to happen with a family member too. That's why it's important for individuals to have earlier discussions around these sorts of things with other family, particularly if they have a chronic condition. What's starting to come into news reports, and I think is largely unhelpful at this stage, are 'what ifs' about what happens if there are limited resources. All I can say is that no doctor operates on a simplistic basis of someone's age or whether they have a specific condition. We are used to managing limited resources with things like transplants, on a day-to-day basis, so it's not a new thought process. This is not a new way of thinking by doctors and it's always done in groups. People shouldn't be anxious they are going to be labelled and then treated in a certain way. They can feel confident that people who know them will have been involved.

Ammar:

I would agree with everything Martin has said. It's important to have planned ahead. You can put an advanced care plan or advance decisions in place, or at least have discussed your wishes with your family – that's important – but no doctor works on an algorithm without thinking. These discussions are all based on the individual's wishes and the actual circumstances happening at the time. These discussions

would be done with the patient if possible, and if not then with a family member. Ideally if advance decisions have been made and recorded by the individual previously, this can help guide things as well.

Chris:

I agree and would emphasise the point that Martin started with, that extremely vulnerable is about ensuring that people can access support when self-isolating. Shielding the vulnerable has been really beneficial in supporting people, but it doesn't really translate into the hospital setting. It's not a phrase that really means anything in that environment. As has been said, the decisions about what to do are based on the individual preferences of the person affected by the condition, and what their wishes are. So it's important to record them and tell those around you what you would want, then to discuss these wishes with the multi-disciplinary teams in the emergency setting. That way, everyone working together can come to a joint decision about what is best.

Summary

Nick:

Thank you everyone for your time today. Your support and dedication and the information you have provided today is fantastic. Everyone affected by MND will be hugely appreciative of your time and your dedication, so a big thank you from me on behalf of our community.

Further information

See our MND Association webpage about coronavirus, including this interview on video at:

www.mndassociation.org/coronavirus

Contact our MND Connect helpline as follows – the helpline team can answer questions and help with guidance on services:

Telephone: **0808 802 6262**

Email: www.mndassociation.org/mndconnect

See more about our services and information at:

www.mndassociation.org/support-and-information