



COVID-19: IMPACT ON CARE GLOBALLY



COVID-19: IMPACT ON CARE GLOBALLY AND RISK FOR PEOPLE WITH ALS/MND

On Thursday, April 9th a webinar with leading ALS/MND Global Clinicians took place. COVID-19 and its impacts to the ALS/MND Community have been felt globally. This webinar answered questions about susceptibility and ALS/MND, and the impact to care globally.

Moderator: Sara Feldman, Chair, PALS & CALS Advisory Council, International Alliance of ALS/MND Associations

Panelists:

- Dr Nortina Shahrizaila, Kuala Lumpur, Malaysia
- Dr. Paulo Kimaid, Campinas, Brazil
- Dr. Adriano Chio, Torino, Italy
- Dr. Christopher J. McDermott, Sheffield, England
- Dr. Jinsy Andrews, New York, New York

Welcome: Calaneet Balas, Chair, International Alliance of ALS/MND Associations

VISION: A World Free of ALS/MND

PURPOSE: The Alliance is a global network of ALS/MND associations informed by PALS/CALS, that builds capability for its members and connects to external stakeholders.



Introduction: ALS doesn't stop, and so neither do we! The International Alliance of ALS/MND Associations have put together some resources about COVID-19 and they can be found at the website www.alsmndalliance.org. Last week we examined Research and Clinical Trials with respect to COVID-19, and that webinar recording, as well as a summary paper, can be found on the Alliance Website. In addition to the Alliance resources, you can link to webinars by NEALS, MNDA and other member organizations who have done some excellent work in this area.

This webinar focused on CARE and we were honoured to have some of the top clinicians from around the world to share what is happening in their areas.

Note: This document is not a verbatim transcript of the call but a blended Question and Answer format to capture the main themes.



- 1. The diagnosis of ALS/MND puts someone in the “at risk” category for complications from COVID-19, particularly because of the compromised respiratory system. What is it that you are telling people living with ALS/MND in regards to a) any increased susceptibility for contracting COVID-19 and b) precautions they or their family and caregivers should be taking to decrease the potential for contracting COVID-19?**

A lot of patients ask “how am I at increased risk” and sometimes there's some misunderstanding that they might be immunocompromised, but to clarify, because the muscles can be weakened by ALS/MND, especially the ones that help you breathe, it can make it difficult and life threatening if the virus is contracted. The susceptibility to contamination is the same for anybody, but the intensity of the disease can be worse due to the restrictions imposed by ALS/MND and therefore everyone needs to focus a lot on prevention strategies to prevent getting the virus altogether!

It seems very simple when the Centers for Disease Control in the USA, and other global agencies, put out recommendations for prevention, but often it requires a more thought and meticulous detail in terms of thinking about how to prevent the infection. Our recommendations for people living with ALS/MND are to practice meticulous hygiene, and would include:

- avoid contact with sick people, avoid leaving the house, and shelter completely at home
- avoid any nonessential travel
- avoid going to a clinic, use virtual communication (telemedicine) wherever possible
- stock up on needed medical and nutritional supplies
- stock up on over the counter medications
- follow regular recommendations of cleaning and disinfecting everything in the home
- wash hands and avoiding touching the hands, nose, and mouth as possible
- get vaccination for other types of viruses causing respiratory diseases so as to avoid more than one infection
- do meticulous forward thinking and planning in conjunction with your clinic if you need a feeding tube, blood draw, or something that can't be done at home and requires a visit to a hospital (some jurisdictions have non - COVID-19 designated hospitals that can still do urgent interventions)

In addition, for ALS/MND patients, there are recommendations for caregivers. In this time where nonessential travel is limited, try to identify one primary caregiver. In many cases this means that family has to become the primary caregiver to avoid exposure from caregivers that may be travelling between homes and may be using public transportation. That primary



caregiver should also follow the same recommendations as the patients to avoid contracting the virus, which means that the caregiver also limit their travel outside, and designate somebody else to get groceries and/or have them delivered. Families should also identify a backup caregiver so in situations where the caregiver is not well, or has some other issue, or has contracted the virus and has to be removed from the home, the back up caregiver can be contacted. Caregivers should follow all the hygiene recommendations and all caregivers should wear a mask.

There have been some advocacy issues that have arisen from this issue. For example, in the UK, the government has a scheme for what they class as highly vulnerable people and there's a list of a predefined conditions, which unfortunately MND is not on. There's a huge amount of lobbying on government through the MND Association clinicians and patients to have MND added to the list.

- 2. I'd like to go around and find out what's happening at clinics in your areas in regard to medical care...are you doing virtual visits, telemedicine, or something else? How is care being provided in your center at the current time? Does this include the multi-disciplinary team? How has this been well received by PALS and CALS?**

Dr. Chio: Starting March 6, which is 40 days ago, we were asked by the hospital to close all our visits so we decided immediately to move to telemedicine to take care of our patients. From the 6th of March to the 1st of April we had 144 visits already scheduled for our patients. We typically see a patient every two months. We immediately started to call them by phone to ask if there is a possibility to have a Skype call or other types of virtual calls and we were able to do 80% of visits using this methodology.

We modified how we did a neurological visit from the beginning so that we could modify therapy. We called to see how the patient was and we are lucky because ALSFRS can be done in that way. We also asked the family if there were more problems related to the swallowing and/or respiration. We could ask the patient to come to the office if there was any clinical important modification, and we ended up with seven or eight with hospital visits. We could start a non-invasive ventilation for three of them because the pulmonologist was available to do that.

Our Allied Health Professionals were able to move their visits to Skype including our psychologist, our speech therapist, and our social worker. They are still working with the patients and their families in that way now as we begin to emerge from COVID-19. This also included the ability to prescribe equipment for communication, as an example. We tried to



preserve our connection to our patients, and telemedicine is not the same as face to face clinical care, but the modifications to therapies have been well received by patients. We have a follow up questionnaire to all visits and they would indicate that the patients are happy with the care that we are able to provide during this time.

We also have a real example where telemedicine has been used successfully for a very difficult decision. There was an individual who was at the point of having to make a decision about tracheotomy or not and we brought in all the relevant people on the video call and came to a decision. We are allowed to take instructions via video call and the patient was happy with the outcome.

Dr. McDermott: Routine face to face appointments stopped about a month ago and we adopted a similar approach with telephone consultations and some video consultations depending on what technology offering the patient has at home. Some of these systems are not overly easy to use but it allows us to triage patients who might need a face to face interaction either with a therapist or with a neurologist. We are able to deal with most things remotely.

Similarly, to what others have mentioned, psychotherapy support services are continuing online. One of the biggest challenges is how we monitor patients on Riluzol. We take a pragmatic approach because we don't want to expose people to the risk of coming out to have blood test done and we don't currently have the facility to do the blood draws in a patient's home. What we'd be doing for patients who are well established on Riluzol for over six months is we just continue with it, because their previous blood levels have been fine. We are pausing starting new patients on Riluzol at the moment, and we're keeping that under review. Hopefully there will be some clean facilities being opened soon where we might be able to do blood draws away from the main hospital. Once that is settled we might then be able to have our patients go to those clean sites for blood draws, then new patients can also start.

For new patients, new diagnosis, we're able to do the initial consultation and take much of the history from a medical perspective and neurology perspective over the phone and then if they are earlier on in the disease course, and there's no symptoms suggestive respiratory failure, we bring them in for a face to face follow up on conversations, allowing examination. I prefer face to face discussions about giving the diagnosis for MND. It's not something I would be comfortable with doing over the phone or through video consultation so we're still trying to do face to face visits for this. If we had an individual who was presenting quite late in the disease course and was doing quite poorly, we may need to think of a different strategy rather than risking bringing that patient with a more advanced disease to the hospital where they risk exposure.



Dr. Shahrizaila: For about six weeks now, all the appointments have been postponed for 3 months. What we've done is switching to phone calls and doing ALSFRS through that method. Similar to others, we are identifying patients who are a bit more critical, so evaluating the breathing and the swallowing aspects, because those are two things that we hope to be able to intervene on if we need to. Although, we are one of the hospitals that's actually looking after the COVID-19 patients, we do have gastroenterologist who can do gastrostomy if it's required but we haven't needed to do that so far. With regards to the non-invasive ventilation we have had to initiate that on two occasions. We work in partnership with MND Malaysia, which is the patient advocacy group, and they are loaning the equipment for free to the patients because it's not really a device that you necessarily can get automatically from the government.

What we've done is get the patient to send us a video of them breathing, and then we will put them in touch with the provider. The provider will actually be the ones that go to the patient's house, and then we will try and do it over a video link to advise with regards to setting up the NIV - that's without the patient having to come in. That's one of the things that we've been able to do fairly successfully. Then of course the provider of the NIV machine will be able to tweak the settings or troubleshoot much better than I would, for instance. That's something positive that we've been able to do working with MND Malaysia and also with the palliative care team, who have been instrumental with initiating a lot of the respiratory discussions and helping with end of life issues.

With regards to new patients, we have phone calls and conversations. If it is very early then we just say, why don't you wait until the movement control order is lifted and things are little bit more stable and we will see you then. In situations where the patients have been admitted elsewhere, it is a little bit tricky because until you confirm a diagnosis of MND yourself, you don't really want to be in a position to start commenting on end of life issues. When you've never seen the patient, it could be lots of other things that mimic or that potentially may have been missed.

Most of the time you're talking to the carers and they've been quite appreciative because they wouldn't get this time with general neurology clinics normally, because they have over 200 patients, but we can do that for the MND patients, and so I think the patients and carers certainly appreciate this.

Dr. Andrews: I think in the US and specifically in NYC we have a unique challenge with Edaravone. We have patients that have lines already in place and have been taking that particular medication (it's called Radicava here in the United States). Like others, we have trouble getting patients to labs to monitor liver function. For Edaravone, a certain percentage of patients get their infusion at home. There is a pharmacy that would deliver the medication at



home and the family does the infusion for those patients – those patients are able to continue. There is a percentage of patients that need to go to an outpatient facility to get their infusions of Edaravone and that's posed major challenges, because a majority, if not all of the infusion centers, are closed and they're not able to receive it. The guidance right now within New York City among the centers, and also the veterans' administration for our former military personnel, is to hold on to any infusions that would require them to either go into a hospital or to an outpatient facility, until it's safe to do so. This took a major discussion of risk versus benefit and it's challenging and disheartening for patients who really want to continue. Of course the added challenges for new patients, who we might have seen in person and made the diagnosis and discussed Riluzole and Edaravone, is we can't even get an access for them. Sometimes it requires a pic line or a port catheter placed and we cannot do that right now in the New York city region. Similar to Brazil, there might be small community hospitals that are a little bit further out that may be able to do urgent gastrostomy for patients who are in need, but even then for patients with in New York city to go out, those facilities are then concerned about patients who might be infected coming, so that poses a hurdle for them. They have to seek out testing and it is fairly difficult at this point in time to get if they don't fit the algorithm for testing. We do have some unique challenges here in New York city that may not be even true for the rest of the United States.

I will agree with all of the panelists about video visits. We actually were transitioning in February to a new hospital electronic system that had video capability, but we had not started it yet, and the pandemic has forced us to do this. Because there was a state of emergency declared in New York, and a lot of executive orders by our government, it alleviated some of the burdens that are embedded with video visits. For example, if a patient resided in a different state, and I don't have a license in that state, I could not do a video visit, but now I can under these executive orders. Also, video visits were only meant for follow up visits, but I can do them for new patient visits now as well. Although, as others have mentioned, there are challenges to making a definitive diagnosis by video, especially if I can't get an EMG properly or if I can't actually physically examine somebody. That is the downside, but the positive is that we have been able to maintain the number of visits. For example, today after this webinar I will see 12 patients by video. We are able to conduct a multidisciplinary visit, we have provisions to do it via zoom conferencing, and so we create breakout rooms, and all of our practitioners go in and out of these virtual rooms. We follow up with a team meeting and our general neuromuscular clinic and our clinics run like this. We have some connection through our electronic health system so we've been able to maintain a good level of care. The one added thing that I personally enjoy is that I'm able to see people's home life, their children, their pets, their hobbies, so I have learned something that I don't normally learn in the office setting about people! I'm thinking that telemedicine may even continue after this.



Dr. Kimaid: In Brazil, telemedicine was under regulation when the Pandemic reached us. Brazilians are used to using various media to “talk” to their doctors, like WhatsApp, despite the lack of adequate information safety. The common use of mobile media such as this allows direct contact with the doctor without the need of a computer. But some telemedicine platforms are offering their services for free during the pandemic and the adhesion is massive in all medical fields. The Institute will start the service next week, but the other professionals (nurses, psychologists, social services...) are already using teleconferencing. The IPG also followed the direction of the International Alliance of ALS/MND Associations, asking the support of the Brazilian government to include ALS/MND patients as being extremely vulnerable, and they immediately answered us, inserting not only ALS/MND patients in the priority list but all neuromuscular diseases. One of the important measures we started, was to commence vaccination for H1N1. In Brazil, patients are very comfortable with the use of telemedicine. It seems to me that we will be adapted shortly. Another interesting tool is the App of the Institute Paulo Gontijo which we had already introduced earlier this year.

- 3. Being hospitalized is often scary for people living with ALS/MND and was even before this pandemic. The ALS Association recommends that you have a GO Bag ready that contains all the necessary medical information and warnings, as well as instructions on how to communicate. The MND Association in the UK also recommends that people have a fully charged cell phone and charger, as there may be no opportunity for a caregiver to go with you. Are there any other recommendations if someone has to be hospitalized?**

Patients going to hospital should bring information with regards to who their original ALS/MND physician is. This is helpful if they need to be admitted to the hospital because the doctors that are seeing them now may not have their background medical history. It's really important that the doctors are able to speak to the primary ALS physician especially when there are already advance care plans in place for some patients.

If a patient is going to be admitted in a hospital that is managing COVID-19 patients then they will not be allowed to have carers or visitors, in order to minimize the risk of spread. That means that where possible you want to try and work with the nursing staff, because it's good to have face time, or some way of doing virtual visits. It's really important that all of that is addressed ahead of time and preparations are made for that to be made available.

The GO Bag is a great idea and it is a bag that you keep at your back door that has all your essential items in it including a charger for your cell phone. One other thing that is also



recommended is that you temporarily unlock your phone so that if you do need to FaceTime, but you aren't able to communicate, your password there is not a barrier to communication. The GO Bag should include such items as food, water, a first aid kit, letter or picture board, adaptive equipment, and batteries. If your PALS can not speak, please include something in there that explains how to communicate.

- 4. We have heard from our care teams globally that end of life discussions are more frequent now. Have you noticed that in your clinic and if so, how are you supporting families through this discussion? (We recognize that this is different in most jurisdictions and a very personal and sensitive topic.)**

A feature of good care for people living with MND and ALS is providing frequent opportunities for them to think and discuss about the future in terms of prognosis options for interventions as the disease progresses and wishes around end of life. Part of enabling those discussions is being sensitive to whether an individual is ready to have those conversations. There are often different triggers throughout someone's journey with motor neuron disease (ALS) when these conversations are necessary. The COVID 19 crisis in some ways is all of those triggers. It's good to always be talking openly about these things. What would we want it in different circumstances; talk to family, talk to friends, talk to those involved in your care so that everyone has a good idea about what your wishes are. In some respects, the COVID-19 situation is just making us have conversations which are a good part of organized care anyway.

These conversations can happen in the telemedicine setting with multidisciplinary team visits so that patients can make advance care plans and they can be recorded in their healthcare records if they wish. It's important that people have these conversations so people are aware of what they want and just as importantly, what they wouldn't want.

- 5. A question came in while we were talking which is about the double hit of the COVID-19 pandemic and also a lack of new diagnoses being able to be made. Do you think we'll see a dip in the number of people who are in the pool for clinical trials?**

There may be a delay in people getting the diagnosis, but it's unfortunately not a difficult diagnosis to make as it doesn't really require testing. It needs a conversation history and an examination that can exclude the mimics and other causes because that gives us the confidence and reassurance that the news that we're giving is the correct news



The main change will be, there will be a delay I think in diagnosis for some people which will be challenging and cause uncertainty. This will be difficult but I think we won't see a dip in how we are picking up cases in the long run

In Brazil no challenges to new diagnoses.

6. One other question that came in is the request to talk about the impact of caregiver mental health during this time, this sheltering in place, and this increased caregiving.

There are increased mental health challenges for everyone but it is even more difficult for a caregiver because they have to face the disease of their relative and they face the fear of passing the virus on to their loved one. We can help them most by assuring them by phone or video call. To be home alone is not the best for anyone!