

Coronavirus Disease Outbreak

COVID-19



FREQUENTLY ASKED QUESTIONS ABOUT COVID-19 AND OUR ALS COMMUNITY

Q: *How might COVID-19 impact someone with ALS specifically?*

A: Even if you are young and otherwise healthy, anyone with ALS is at very high risk to get COVID-19 and have complications. Most at risk are those with any respiratory muscle weakness and/or bulbar involvement. Although ALS patients in general have a good immune system, the most worrisome thing is the lack of a strong cough to clear away the secretions that may accompany the viral infection. Those secretions may stay in the lung and lead to pneumonia. So make sure you are avoiding contacts as much as feasible (social or physical distancing) and if you have been prescribed a cough assist and/or breath stacking device, use them religiously at least twice daily. — *Dr. Lou Libby*

Q: *What precautions should people with ALS, their caregiver, and family members take?*

A: People should do what they can to reduce their risk of exposure. Most importantly, handwashing and avoiding touching your face makes a big impact in avoiding a respiratory illness. Staying 6 feet or more from people is also helpful. Your local community may even suggest staying at home, or avoiding groups of a certain size, and we encourage you and your family to follow local health advice carefully. Also, avoiding preventable illnesses, like the flu, is very helpful. Your family and caregivers should check with their doctor about getting a flu shot, if they have not already. — *Dr. Neil Thakur*

Q: *I have been coughing for months due to my swallowing problems from bulbar ALS. How will I know when my cough is possibly due to the Coronavirus?*

A: Many PALS have a chronic cough. If you have the development of other symptoms of the coronavirus infection such as fever, body aches, sore throat or nasal congestion, then you need to be concerned that it is coronavirus and not just your usual ALS related cough. — *Dr. Lou Libby*

Q: Should extra precautions be taken when handling packages, mail, or store-bought items that could have been handled by someone with COVID-19? If so, what would be the best way to handle those items?

A: It's really important for everyone to wash their hands thoroughly and avoid touching their face as much as possible, because we do not know who might be infected or what they touched. The virus has been shown to live on surfaces, especially hard surfaces like glass or plastic, for up to three days, and cardboard up to 24 hours. If you have a particularly strong concern about a surface or a person that touched it, spray the surface with a cleaning spray or wipe it down. Paper or cardboard through the mail is low risk, because of transit time and minimal handling. Content in a package, like a metal can, could in theory have some contamination on it and could have been handled less than three days ago, so has some chance of some contamination. I have the strongest concern for hard surfaces that are touched by a lot of people, like a shopping cart handle. I would just assume they are contaminated and wipe them down if I can. — *Dr. Neil Thakur*

Q: My family just traveled by car back from Texas to Minnesota. Can I see them or do they need to stay away?

A: Excellent question and it is very difficult to balance need for protection from the virus and our social needs. I dislike the term social distancing and am using the term physical distancing. I think for your protection you should ask them to stay away if they have any symptoms of coronavirus — cough, fever, achiness, sore throat etc. But if they have been healthy, extreme social distancing is appropriate — at least 6 feet away from you and do all the things you hear about — washing hands, covering sneezes and coughs and minimize contact with anything others have been touching. — *Dr. Lou Libby*

Q: What are you doing for your family?

A: I live at home with my wife and adult son — we are all healthy but I am 70 and only work part time (for now) seeing out patient ALS patients. We are practicing extreme social distancing (I prefer the term physical distancing) and avoiding anyone else that we can. We speak to neighbors across the yard and spend extra time on the phone talking to friends. I am working in my office but we are rapidly converting to telehealth visits as much as possible. We avoid going out other than walking the dog and taking a long hike in the afternoon when I have the time. We have stocked up for about 10 days — balancing our needs and avoiding hoarding.

The reason for the extreme social (physical) distancing is mainly to “flatten the curve”- keep the surge to a minimum so the hospital and all my critical care colleagues can stay safe. It also protects us and if I have to see some ALS patients, it minimizes the chances that I will transfer the virus to them. — *Dr. Lou Libby*

Q: What is the impact of this across our chapter network?

A: Chapters continue to reach out to families on an individual basis. They have paused group meetings and restricted in-person meetings to those with an urgent need. Chapters are providing information and services via telephone, email, Facetime, and Skype. Visit your chapter's website or telephone/email your chapter care service coordinator directly for additional information. – *Cynthia Knoche*

Q: What should someone do if their caregiver is exposed to the virus or diagnosed with the virus?

A: This is a very difficult question that depends on the situation. If at all possible, replace the caregiver. But I also know that caregivers are sometimes irreplaceable or live in your home (and sleep with you). If they live with you and are not replaceable, be extraordinarily careful about hand washing every time they touch you or are close to touching you. This might mean 5x hourly with all the turning and adjusting needed by some PALS. They should wash their hands before touching you, and after touching you. This is the one situation where I would also suggest the caregiver wear a mask – a simple mask, not the N95 type. The simple mask will prevent any coughed or sneezed particles from spreading as easily. And they should socially distance themselves when possible including sleeping in a different room if possible. I hope this does not happen but with the expectation that a majority of us will get the virus over the next few months, it is highly likely.

Q: I am only 35 and in great health other than ALS. I understand that my age puts me in a very low risk group for critical illness and death from the coronavirus. Does ALS affect my immune system and make me high risk?

A: Yes, age 35 has been considered low risk based on data from China. However, recent reports from Seattle suggest that young adults are still at risk and some are dying. In Seattle, they are emphasizing that this virus is dangerous for everyone, not just the elderly and unhealthy. Of course, the risk is highest in the older and unhealthy. But Seattle has seen young adults develop the severe complications and even die. We are all in this together and we have to do whatever we can to protect ourselves and right now that means social (really physical) distancing. – *Dr. Lou Libby*

Q: Should I and my family members be taking our temperature every day?

A: I do not think there is an absolute right answer here. My practice and my hospital are requiring every person entering to have their temperature taken and answer a few questions about symptoms. If there is a fever or new symptoms suggestive of the Coronavirus infection, they are asked to go home or seek care as needed. This is to protect the hospital and clinic patients and medical personnel. If I had ALS, I might do the same thing for anyone coming to care for me or any other necessary visitors. –*Dr. Lou Libby*

Q: Is it safe to allow the home care aide to visit me or should I cancel and have a family member assist me?

A: Excellent question there is no right answer for every situation. There are many implications to cancelling your home care aide. Of course, from a personal safety point of view, minimizing contacts with people in general does lessen the chance of getting the virus. But your family member may or may not have the ability to do what the caregiver can do and if you do not get the care you need, it can be dangerous also. And your family member may get physically or emotionally tired if it is too much of a burden. And if it is a valuable caregiver, they may feel deserted and not want to return when you need them later. So I think it depends on your personal situation and deserves a thoughtful conversation with your family. The fact that you are asking suggests you have already been thoughtful about this. – *Dr. Lou Libby*

Q: Should I ask all home care workers like aides and nurses to wear masks when they visit?

A: When considering this question, we have to balance the need for protection from your caregivers with the needs of our frontline health care workers. Masks are at a minimum and hospitals right now are concerned that they will run out in the next week or two. I would ask your caregivers to wear a mask if they have symptoms of Coronavirus and you have no choice but to have them take care of you - for example, a member of your family and you have no one else to care for you. Otherwise, there is little benefit to you and we risk running out of facemasks for the health care workers who will be taking care of all of us when we get ill. – *Dr. Lou Libby*

Q: My clinic team was talking to me about respiratory support equipment – is it still available?

A: A number of larger respiratory home care companies have paused routine home visits however, they continue to serve patients on an 'as needed basis', and are accepting newly referred patients. They continue to screen both patients and staff for recent international travel or fevers. – *Cynthia Knoche*

Q: Is it safe for my grandchildren to visit me?

A: Such a hard question when it comes to family visits. Social isolation is not what any of us needs in these times. But we also know that children carry many viruses and with this epidemic there is fear that they may carry it and have few symptoms so may be a source of spreading the infection without knowing it. And most ALS patients are at high risk for getting COVID19 and having complications. Personally, if I had ALS and any respiratory compromise (for example low breathing test numbers <70% or need for respiratory equipment like AVAPS, Trilogy, Cough assist), I would avoid every contact possible, especially young children who do not understand physical distancing and hygiene. I would use Skype, Facetime or other means to see and communicate with people, especially grandchildren who are probably better at using those devices than most of us. – *Dr. Lou Libby*

Q: My clinic appointment was changed to a “telehealth” appointment-how does that work?

A: If your clinic or medical provider has established a telemedicine capability, this will allow you to connect with your provider via video call (similar to what you might use for family and friends) or by phone if a video connection is not possible. This will allow your provider to conduct a ‘visit’ with you while you remain in your home or other location. This is especially important in the current environment where you will want to lessen your risk to viruses. Contact your provider to find out the specifics of how they intend to implement this option. – *Kim Maginnis*

Q: Is it safer for my caregiver to go to the store during “Senior Hours” or to get groceries delivered?

A: We reduce our risk by reducing our exposure to other people and the things other people may touch (like door knobs or computer keyboards). Getting things delivered has less risk than going to a store, and going to a store when it is less crowded, like during ‘senior hours’, has less risk than going during a busy time. – *Dr. Neil Thakur*

Q: We already have respiratory equipment, but what about the supplies; tubing, masks, suction catheters – are they in short supply?

A: DME providers report they have current inventory, however supplies are beginning to become low, and their orders may be filled on a delayed basis, or only partially filled. It would be important to follow any home cleaning of your equipment and supplies, and to make sure your supply order is up-to-date, even asking your DME company to provide supplies for the next 30 days now if available. – *Cynthia Knoche*

Cynthia Knoche is director, chapter care services. Cynthia maintains her license as a registered respiratory therapist and has spent the last 13 years assisting ALS Association chapters across the country with development and delivery of their care service programs.

Dr. Lou Libby is a pulmonary and critical care physician with the Oregon Clinic and the lead pulmonologist at The Providence Portland Medical Center ALS Center. Dr. Libby also serves on the Association’s National Board of Trustees.

Kim Maginnis is senior vice president of Care Services. Kim has worked in the healthcare industry for more than three decades, and her resume includes positions at Inova Health System, the Veterans Administration and Harvard Community Health Plan.

Dr. Neil Thakur is executive vice president of Mission Strategy. Dr. Thakur is also an epidemiologist and while he is not an expert on COVID-19, he is a public health researcher who got his PHD at Yale and later worked for many years at the NIH.

