# **ALS_Logo_BlueCOVID-19 & ALS: Frequently Asked Questions**

# **Home Health Care, Medical Appointments and Urgent Care**

We recognize that as the COVID-19 (coronavirus) pandemic continues to evolve and new cases are diagnosed, concerns surrounding infection and prevention measures continue to grow as well. We continue to consult with physicians at our Lois Insolia ALS Clinic at the Les Turner ALS Center at Northwestern Medicine  to determine recommendations specific to people living with ALS. Please continue to visit our [Coronavirus (COVID-19) Information & Updates](https://lesturnerals.org/support-services/coronavirus/) page for the most up-to-date information from the Foundation.

The International Alliance of ALS/MND Associations **recommends that you discuss any individual concerns you may have with your local health and social care team. They will be able to give you advice and information which takes into account your specific circumstances, the surrounding environment and local eco-system challenges.**

### I HAVE IN-HOME NURSING (CARE AND/OR INFUSIONS). SHOULD I ALLOW THEM TO ENTER THE HOME? WHAT PRECAUTIONS SHOULD WE TAKE?

***CARE:*** ALS clinicians recommends limiting non-necessary visitors to your home, some aspects of home healthcare are essential. If possible, limit the number of outside healthcare workers that enter your home. Ensure your home health nurse(s) takes all necessary precautions including hand washing and wearing personal protective equipment (PPE) including properly fitting surgical (paper) masks and gloves. In addition, nurses who are sick, or have had potential exposure to someone infected with COVID-19 should NOT work in your home. If you have any concerns, you may reach out to your home healthcare company to discuss a plan that is safest for you or your loved one.

***HOME INFUSIONS:*** If a person living with ALS receives infusions at home, you may continue to do so, if possible. Take the same precautions as mentioned above, and if you have any concerns about receiving the infusion, please contact your ALS clinic

**MY CAREGIVER CARES FOR OTHER PATIENTS AND/OR HAS OTHER JOBS SHOULD I BE CONCERNED?**

It is important to have open communication with your caregiver to better understand additional risks you may be exposed to and help limit major disruption to your life. If you are uncomfortable with the potential risks, please call the home health agency for additional guidance. Below are some tips to help mitigate risks:

* Caregiver washes hands immediately upon coming into the house and regularly throughout your shift.
* Caregiver to wipe down and clean surface areas, doorknobs, medical equipment and tubing and other bacteria/viral-ridden areas during your shift.
* Caregiver to monitor use of supplies and prevent waste as much as possible, while also protecting caregiver and family.
* Caregiver must immediately call if members of their household or other patients they care for have signs and symptoms of a respiratory infection. The caregiver should not report to work.
* Request that caregiver leave an extra set of clean clothes to change into while working.

## SHOULD I QUARANTINE MYSELF FROM HOUSEHOLD MEMBERS WHO WORK OUTSIDE THE HOME?

For adults living with you who are unable to work from home, consider decontamination practices upon returning home: removing clothing worn outside of the home, immediately showering upon arriving at home, practicing hand hygiene, covering their cough, wiping down frequently touched surfaces and staying 6 feet away from you. Minimize contact with at-risk people in the home.

## I HAVE (CLINIC, PHYSICAL AND OCCUPATIONAL THERAPY, INFUSION) APPOINTMENTS AT THE HOSPITAL/INFUSION CENTER. SHOULD WE CANCEL OR KEEP GOING?

Center for Disease Control and Prevention recommends cancelling all non-essential appointments. Please check with your ALS clinic team to see if there are options for virtual care during this time including a phone consult or video visit.

Talk to your ALS clinic team and discuss an alternative plan, such as physical therapy or occupational therapy you can do from home. If you have concerns about traveling or going to an infusion site, consult with our ALS clinic team about the safest option for you.

## WHAT IF I AM SCHEDULED FOR A FEEDING TUBE PLACEMENT OR AN EXCHANGE?

The ALS clinic team will be reaching-out to you to discuss your options since your feeding tube placement may need to be rescheduled. You can also contact the ALS clinic team directly.

## WHERE CAN I FIND MORE INFORMATION ON CARE RECOMMENDATIONS FOR ALS RESPIRATORY CARE DURING THIS OUTBREAK?

**If you do become ill, DO NOT GO TO THE EMERGENCY ROOM OR URGENT CARE BEFORE SPEAKING WITH YOUR ALS CLINIC PROVIDER FIRST.** Depending on the situation, they may try to manage the illness remotely. If it is necessary to come to the hospital, they may provide unique instructions for entrance and triage to minimize risk of exposure to COVID-19. [Please visit our website for more information on best practices for respiratory issues in ALS.](https://lesturnerals.org/support-services/coronavirus/care-recommendations-for-respiratory-issues/)