

The ALS Association Greater Chicago Chapter Care Services Support Newsletter Spring 2020

ALS IS NOT CANCELED... ...so neither are we.

We are all working remotely to continue serving our friends living with ALS and their families. Our programs and services are ongoing and being conducted according to recommended guidelines for everyone's safety.

Please don't hesitate to reach out with any needs, questions, concerns or even if you just want to chat! We can't wait until we can all be back together again!



ALS Association Greater Chicago Staff at our work-from-home stations, ready to serve YOU!

While we are not physically at our office, we remain dedicated to you and our cause. Reach us Monday-Friday from 9:00am-5:00pm. Don't know who to call? Start with our office line or info@alsachicago.org to get directed.

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Coronavirus Disease Outbreak COVID-19

These FAQs were developed from the March 19 Connecting ALS podcast, “What the ALS Community Needs to Know Right Now About COVID-19 ...” Listen at ConnectingALS.org

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 COVID19 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.



The Healy Trial: The First-Ever ALS Platform Trial

Joumana Barody, RN, BSN, Director of Care Services



The ALS Association's research program aims to hopefully speed breakthroughs and accelerate drug development. **This research program is currently funding more than 70 promising active research initiatives around the world.**

One of the strategic commitments of the ALS Association that is expected to expedite breakthroughs is the first ever ALS platform study. The ALS Association has committed \$3 million – *\$1 million each year for the next three years* – to this important study taking place at the Sean M. Healey & AMG Center for ALS at Massachusetts General Hospital in collaboration with the Barrow Neurological Institute and the Northeast ALS Consortium (NEALS).

A platform trial is a clinical trial in which often multiple treatments are tested and evaluated simultaneously against one placebo. This platform trial model, already proven successful in the cancer field, will speed-up the process of testing for therapeutic treatments by allowing the simultaneous evaluation of several therapy candidates and increasing patient access to these studies. Typically, with a single drug trial, it can sometimes take up to 12 years to test 10 compounds. With a platform trial on the other hand, researchers can do it in just four years because they can test multiple drugs simultaneously. Moreover, a platform trial allows the use of shared infrastructure, such as common data and sample collection processes. Another benefit of the platform trial is that there is only one placebo group for the multiple interventions tested at that same time – rather than a placebo group for each of the tested therapies. These advantages as well as central governance within the platform trial will lead to operational efficiencies and time and cost savings. This type of trial allows for new therapies to be added to the trial as they become available and approved, thereby decreasing the gap in time from identification of an exciting therapy to testing. It also provides greater opportunities for finding effective treatments and ultimately, a cure.

The Healy Center was created in 2018 and launched about a year later. A request for proposals brought in about 30 drug applications from 10 different countries. Five of these drugs ended up being chosen for inclusion in the platform trial, three of which were recently given the U.S. Food and Drug Administration's (FDA) approval for use in the trial. The trial is governed by a Master Protocol, which is a common protocol that works for multiple therapies.

The three drugs that received FDA approval for use in the platform trial are:

- **ZILUCOPLAN**, by Ra Pharma: a small molecule that works against a component of the immune system - complement overactivation;
- **CNM-AU8**, by Clene Nanomedicine: a liquid suspension of gold nanocrystals aiming to improve nerve cell survival and function;
- **VERDIPERSTAT**, by Biohaven Pharmaceuticals: an oral small molecule that works to lower inflammation and oxidative stress in the brain and spinal cord.

Two additional drugs, Pridopidine, by Prilenia and IC14, by Implicit Bioscience, are expected to be added to the platform trial in the near future. These five therapies were carefully selected by a group of leading ALS researchers and members of the Healey Center Science Advisory Committee. The platform trial will continue to add candidate treatments until safe and successful ALS therapies are found.

The primary endpoint for each of the treatments on this platform trial will be changes in disease severity after six months. This will be assessed by the **ALS Functional Rating Scale-Revised (ALSFRRS-R)** score, which is a measure of daily life activities, such as swallowing, speaking, writing, cutting food, walking, or climbing stairs. The trial also will include several promising biomarkers and outcome measures aimed at developing new tools to evaluate the effectiveness of ALS therapies.

The goals of this groundbreaking project are to greatly accelerate the timelines towards effective ALS treatments and provide greater trial access for all those affected by this disease.

The HEALEY ALS Platform Trial is a collaborative effort, and enrollment in the trial will be available at 54 sites across the U.S. to bring the trial close to people who want to participate. In the Greater Chicago Area, one of the ALS Association's Certified Treatment Centers of Excellence, the **ALS clinic at the University of Chicago Medical Center**, is one of the chosen centers for the Healey ALS Platform trial.

A number of patients interested in the trial have been, understandably, anxious to get started, and have been contacting centers across the US to inquire about their start date. It is important to know that before officially starting enrollment, any trial will need to be approved by an Institutional Review Board (IRB), which reviews the trial and, among other things, ensures that it is safe for patients to participate. Because this particular trial will be conducted in many centers across the country, it has to first go through a central IRB approval process, and then additional review and approval by each clinical site's IRB. After approval, the site's investigators and staff who will conduct the trial will need to be trained. In addition, other matters regarding treatment distribution, safety monitoring, and biomarker development may need to be taken care of prior to initiating enrollment of patients. If all goes as scheduled, it is estimated that the trial will be starting at the end of May or June of 2020.

In Summary

The **University of Chicago ALS clinic** will soon start enrolling ALS patients as part of the HEALEY ALS Platform Trial. The Healey platform trial is a collaborative effort at several sites across the U.S., led by Massachusetts General Hospital. The trial allows the evaluation of multiple investigational drugs simultaneously in a rather short period of time. Trial design also decreases the chance of patients receiving a placebo. Please contact Dr. Rezanian (kreznian@uchicago.edu) the principal investigator, or Shail Bhatnagar (sbhatnagar@neurology.bsd.uchicago.edu) if you are considering participation in this trial.

Joumana Baroodi, RN, BSN, Director Care Services, joumana@alschicago.org

Information on COVID-19 and ALS

Peggy O'Connor, RN, BSN, Care Services Coordinator



Coronaviruses are a large family of viruses that can affect humans or people. They can cause a wide variety of symptoms in animals, but when they affect humans they usually cause respiratory infections. SARS-CoV-2 is a virus that had not been seen in people until it started causing illness in a region of China in 2019. The COVID-19 is the disease caused by this new, “novel” coronavirus.

The virus is new, and researchers are still learning about it. As far as it is currently understood, the virus seems to spread as most respiratory viruses do - between people through respiratory droplets that are produced when an infected person coughs or sneezes.

The virus is highly contagious, meaning it spreads easily and very quickly. Experience with the virus in the U.S. is only recent. We have learned much of what we know of the virus from the experience in countries that have already been affected. Many of the people infected with the SARS-CoV-2 virus will have mild symptoms, including fever, dry cough and fatigue, but will make a complete recovery with rest at home. If the symptoms progress and become more severe, the illness becomes life-threatening. Experience from other countries has identified risk factors for more severe disease and worse outcome. The high-risk groups identified are those over 60, those with compromised immune systems, and those with underlying medical conditions such as high blood pressure, cardiac disease, diabetes, or other serious chronic diseases.

While ALS does not affect the immune system, people with ALS are at great risk for complications with any viral illness that affects the respiratory system. COVID-19 in particular carries the risk of very severe disease in people with underlying illness. In ALS, difficulty with removing secretions or weakness of the muscles involved in coughing will lead to a viral pneumonia, with worsening cough and shortness of breath. If lung congestion reaches a critical point, patients experience respiratory failure and the need for mechanical ventilation. Even with respiratory support, someone with ALS is unlikely to survive a severe infection from this virus.

Given the severe consequences of the disease, it is advised that all people with ALS follow strict infection control in their homes wherever possible. Here are some important guidelines:

WASH YOUR HANDS. DON'T TOUCH YOUR FACE. Hands should be washed before eating or preparing food, after blowing one's nose, coughing or sneezing, after using the restroom, and before and after assisting someone in any of these activities. Caregivers should employ good handwashing both to protect themselves and avoid transmitting disease to the patient, especially when feeding or performing mouth care for a loved one.

LIMIT TRAVEL OUTSIDE OF THE HOME. This includes visits to your physician office. Medicare recently approved payment for virtual telehealth visits with doctors, and other insurance carriers are expected to follow. The technology will vary from office to office, but health systems are working to utilize this tool to meet patient needs without exposing them to the risk of coming to the office. If possible, designate one person in the household to do all of the shopping, and limit those trips to only what is essential.

CLEAN HIGH-TOUCH SURFACES FREQUENTLY. Use a disinfecting wipe or solution to clean surfaces that are

frequently touched by multiple people. This includes doorknobs, light switches, toilets, faucets, countertops, drawer handles, keyboards and phones.

PRACTICE SOCIAL DISTANCING. If you must leave the house, maintain a distance of at least 6 feet from others. This keeps you out of range of any respiratory droplets that people around you may shed. Social distancing for someone with ALS includes not allowing house guests. It is important to strictly limit the number of people you come into contact with.

UNDERSTAND THAT THE VIRUS MAY BE CARRIED BY PEOPLE WHO DO NOT HAVE SYMPTOMS.

The incubation period (the time between exposure and development of symptoms) of the virus is 5-10 days. People who are showing no symptoms may be active carriers of the virus and able to infect those around them. Infection control measures should be practiced by everyone, not just those who are ill.

IF YOU FEEL SICK, CALL YOUR DOCTOR. If it is determined that you should be seen in the office, the staff will direct you how to proceed so as to limit the possibility of further infecting other patients. Do not go to the doctor's office without first speaking to someone, and do not go to an immediate care center if you have a cough or fever that may be viral. COVID-19 is very easily communicated to others, and you put others at risk in the office and waiting room.



There are some additional considerations for those with ALS:

- Where possible, try to have a month's supply on hand of any medication or equipment needed. This includes G-tube feeding supplies and formula, as well as filters and hoses for non-invasive ventilators. Follow your vendor's guidelines for cleaning and replacing all supplies.
- Utilize your airway clearance devices. Chest percussion vests and cough assistance devices are an important part of clearing secretions and minimizing complications of pulmonary congestion.
- Have a backup plan in the case of caregiver illness. If you are working with agency caregivers, ask what their plan is in the case of employee illness. Ask the agency how they are screening employees for illness. If you depend on family members for care, reach out to your support network to arrange for assistance in the event your caregiver gets sick.
- Be alert for changes in your breathing. Shortness of breath is a part of having ALS, and it usually comes on gradually and does not suddenly become worse. ALS-associated coughing is most often noted during meals or in response to pooled oral secretions. If you experience new symptoms of coughing and shortness of breath, especially if accompanied by fatigue, fever, or body aches, call your physician's office.
- If someone in the home becomes infected, they should practice strict isolation and stay in a room separate from the rest of the family. The person with COVID-19 should use a separate bathroom if possible. Tissues should be used for coughs and sneezes, and immediately thrown in the trash which should be double-bagged to avoid spreading the virus. A facemask can help keep from spreading the virus to others. Disinfect hard surfaces regularly. Avoid sharing household items. Wash hands frequently.

- If the infected person is the patient, use the precautions above. If the patient is unable to wear a facemask (as may be the case with severe bulbar symptoms), the caregiver should wear a mask.

Lastly, it is crucial to have your advance directives in order. Given the potential for life-threatening complications of COVID-19 infection, it is important to have your wishes documented. If a person with ALS develops respiratory failure requiring mechanical ventilation, they will not recover to a point that they will be able to breathe on their own again. There will not be a return to the pre-virus level of functioning, as the time in the hospital with critical illness will take a severe toll on all of the muscles and exacerbate the progression of systemic muscle weakness. If a person with ALS does recover from COVID-19 infection, their quality of life will be significantly diminished from what it was pre-infection. Take the time to talk to your family, designate a medical power of attorney, and document your wishes with your physician's office. The Practitioner Orders for Life-Sustaining Treatment form (POLST) and further information is available atpolstil.org. If you need guidance in this process, reach out to your care services coordinator or doctor's office.

Peggy O'Connor, RN, BSN, Care Services Coordinator, peggy@alsachicago.org

Keepin' it Real with Kellie in Central Illinois

Kellie Branch-Dircks, MSW, LCSW, Central Illinois Care Services Coordinator



Right now, everything seems “surreal” but we will eventually get back to a new sense of normal once COVID-19 has been contained. What remains “real” is that ALS does not stop just because of a pandemic - and neither do we! As you all know, in-person support groups and home visits have been put on hold for the safety of everyone involved, but we will be conducting them virtually via ZOOM technology at the regularly scheduled times. In anticipation of the group meetings, if anyone would like to “practice” ahead of the group, please contact me and I would be happy to do a trial-run with you so that you feel comfortable and ready with the program on the day of group. Although I am not doing in-person home visits, I want to assure each of you I am still available to meet your needs.

Please don't hesitate to contact me, and we can set up a video meeting or phone call at your convenience.

There are many community resources being established daily and specific to each county. If there is something you are worried about, having a hard time accessing, or not sure how to navigate during this time of closures and limited resources, reach out to me and we will problem solve it together.

As difficult as these times are, many good things are coming from it as well. The Central Illinois community has always been an amazing support system for each other. I encourage each of you to remember that. You are not in this alone. A friend is just a call away. All you have to do is ask. We got this!

Kellie Branch-Dircks, MSW, LCSW, Care Services Coordinator, kellie@alsachicago.org



Management and Prevention of Constipation in ALS

Gema Ramos, RN



Constipation is defined as having a bowel movement fewer than three times per week generally with hard, dry stools, difficulty with elimination, and bloating. Unfortunately, constipation is a frequent complaint with ALS. It's a symptom that's not directly, but indirectly brought about by ALS. To help manage or prevent constipation it is helpful to know the most common contributing factors.

Some of the possible cause and contributing factors to constipation in ALS in general are:

- Decreased physical activity because of decrease in muscle strength and fatigue
- Decreased dietary fiber intake due to changes in food choices due to chewing or swallowing difficulty
- Decreased fluid intake because of difficulty swallowing liquids or to decrease frequency of urination due to the need for more assistance going to the bathroom
- Weakness in abdominal or pelvic muscles making it more difficult to bear down and push the stool from the body
- Medications to control saliva, (e.g., amitriptyline, atropine) or pain (e.g., codeine) which dry up the stool

To help manage or prevent constipation here are some alternative non-medication recommendations:

- Stay well hydrated by increasing fluid intake including any non-alcoholic beverages, such as water, juices, milk, thickened liquids— a liquid diet does not always contain much water, so drink plenty of water. Aim for 8-9 cups of fluids per day. Try warm liquids, especially in the morning; Senna tea or microwaved prune juice can be helpful. It is important to establish good fluid intake before trying to increase fiber intake. High fiber intake without sufficient fluids may actually aggravate the problem
- Gradually increase dietary fiber intake including whole grain products (bread, cereals, pasta, brown rice), vegetables, fruit, legumes (dried peas, beans, lentils) and fiber supplements (bran, psyllium). Most of the fiber in fruits is found in the skins. Fruits with edible seeds, such as strawberries, have the most fiber. Eat bran cereal or add bran cereal to other foods. Eat prunes (microwaved especially).
- Eat regular mealtimes
- Speaking to your doctor about adjusting certain medications that contribute to constipation
- Good bowel habits including not suppressing the urge for a bowel movement (“heeding the call of nature”)
- Using a “Squatty Potty” or simply propping up the legs on a trash can to elevate it. Having a bowel movement in the natural squat position opens the colon and makes elimination faster and reduces straining.

- Going to see a physical therapist to have you or your caregiver learn colon massage or pelvic floor bowel management. Colon massage is an abdominal massage that when performed correctly, can help loosen up compacted fecal matter so the muscles in the colon can move the waste along in a more effective manner.

Two recipes that may be helpful:

Fruit Paste for Constipation

INGREDIENTS:

1 pound pitted prunes
1 pound raisins
1 cup lemon juice
1 pound dried figs/
1 cup brown sugar
3-4 oz pkg Senna Tea

Steep tea for 5 minutes in 3 ½ cups water and strain. Add fruit to 2 cups of tea and boil for 5 minutes. Add sugar and lemon juice, allow it to cool. Blend in food processor. Enjoy eating fruit paste straight off the spoon. Spread it on toast, or add hot water and make a drink. If the fruit paste is not working (no bowel movements), then increase the amount of fruit paste each day. If the fruit paste induces very loose stools, cut down on the amount of fruit paste intake. Consider taking it every other day in some cases. This can be made and stored in the freezer in ice cube trays.

Prune Juice Cocktail

MIX TOGETHER:

1 cup applesauce
1 cup oat bran or unprocessed wheat bran
1 cup of prune juice

Begin with 1-2 tablespoons each evening mixed with or followed by 6-8 oz cup of water or juice. This should help to soften and regulate your bowel movements within 2 weeks. If no change occurs, slowly increase serving to 3-4 tablespoons. This may be stored in your refrigerator or freezer. 1 to 2 tablespoon servings may be frozen in sectioned ice cube trays and thawed as needed.

Laxatives are often used for the treatment of constipation. Laxatives can be separated into four main headings: softeners, stimulants, bulking agents, and osmotic agents.

- Stool softener: Docusate sodium, dosage of up to 500 mg daily. This medication brings more fluid into the bowel. These can take several days to take effect.
- Stimulant laxatives: Senna, bisacodyl, or sodium picosulfate. These medications have a stimulant effect. These can take effect in approximately 6-12 hours. Glycerol suppositories act as a mild irritant to the lining of the rectum. These can take effect in 15-60 minutes.
- Osmotic laxatives: Magnesium salts and polyethylene glycol. These medications work to increase water absorption into the stool, making it softer, bulkier, and easier to pass.
- Bulking agents: Metamucil, Citrucel. People with ALS should exercise caution with bulk or fiber laxatives, especially if swallowing is difficult. Without adequate fluid intake, fiber laxatives can swell up in the throat, esophagus or intestine, creating a dangerous blockage. They also can gum up a feeding tube unless adequately flushed with water. Follow package directions carefully.

If these measures do not resolve the problem and/or you have not had a bowel movement in 4 days, please consult your physician.

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<https://voice.ons.org/news-and-views/crush-constipation-with-this-old-time-recipe>

https://www.hopkinsmedicine.org/johns_hopkins_bayview/_docs/medical_services/gynecology_obstetrics/bowel_regularity.pdf

Gema Ramos, RN, Care Services Coordinator, gema@alsachicago.org

Smartphones and Tablets as Speech Generating Devices

Stephanie Barb, MS/CCC-SLP



It is no secret that mobile technology – cell phones, smartphones, and tablets – has expanded our ability to communicate, remain connected with our social networks, and perform countless other activities. For those whose speech is easily understood but have limited access to using their hands, iOS 13 has added a new accessibility feature called Voice Control. Voice Control allows an individual to operate their iPhone almost entirely through voice commands. For individuals who have difficulty with verbal speech, smartphones and tablets can serve as lightweight, portable communication solutions. There are a host of apps available that can increase an individual’s ability to effectively and efficiently speak their mind. Many of the apps available for literate individuals are referred to as text-to-speech

apps which convert any message you type into speech. Many of the text-to-speech apps have features to enhance your rate of communication such as word-prediction and access to pre-stored phrases/sentences and are often available at relatively low costs. Of course, there are some considerations when using personal mobile technology as a communication solution such as: off the shelf computers and tablets are typically not covered by insurance and you may need additional hardware such as a Bluetooth speaker or alternative access methods as physical abilities decline. For additional information on using face tracking and eye gaze for the iPhone and iPad, please visit: bit.ly/facetrackingiphone

We always recommend that you connect with a speech language pathologist to determine which hardware/software options best meet your needs. If you are looking at text-to-speech apps, here are a few to consider. . .





Speech Assistant AAC

Fully customizable text to speech app. Categories to organize phrases and a keyboard with word prediction for novel messages. Option to record speech or use tablet voices. Available in 4 languages.

iOS 9.0 or later (iPhone, iPad) \$14.99

Android (Google Play) - limited features Free



Verbally

Text to speech app containing core words, phrases, and a keyboard. Verbally Premium available for added features. Only available in English.

iOS 8.0 or later (iPad) Free

Verbally Premium \$99.99



Snap Core First (Text Page Set)

Customizable communication app including core words, quick phrases, word lists, topics, keyboards, and a new whiteboard feature. Available in 13 languages. Customized content can be transferred to a Tobii Dynavox speech generating device if a change in access method is needed.

iOS 10.0 or later (iPad) \$49.99

Windows 10 version 17134.0 or higher \$49.99



Predictable

Customizable text to speech app. Categories to save phrases, sentences, or message banked files for quick access. Available in 10 languages.

iOS 10.0 or later (iPhone, iPad) \$159.99

Android 4.2 and up (phone, tablet) \$174.99

Windows (laptops and Surface Tablets - phones not supported)



Proloquo4Text

Customizable text to speech app. Access to keyboard, words, and phrases from a single screen. Available in 9 languages.

iOS 12.4 or later (iPhone, iPad) \$119.99

Stephanie Barb, CCC - SLP, Speech Language Pathologist, stephanie@alsachicago.org

Coronavirus Survival Guide: Coping with Quarantine

Kellie Branch-Dircks, MSW, LCSW, Central Illinois Care Services Coordinator



By now, everyone has been impacted by some change due to the coronavirus disease (COVID-19). One of the most difficult changes to our routine is the requirement of being in quarantine. Quarantine requires isolation from doing the things we love to do, being with people we love to see, and lack of availability to resources we need for quality of life.

For those living with and caring for those with ALS, we are the professionals in how to survive. Nevertheless, a review of the impact and how to cope is always helpful.

Hearing about a nationwide “pandemic” can cause fear, anxiety, feel overwhelming, and cause strong emotions. How one reacts to the stress of the situation is individualized to the person’s individual experiences, background, support system, and coping skills. People who may respond more strongly during this time may include the elderly, those with chronic health conditions, children/teens, health providers/first responders, and those with pre-existing mental health conditions.

Common reactions to the stress of a crisis include changes in sleep patterns, changes in eating patterns, difficulty concentrating, preoccupation with your own health or the health of loved ones, increased use of substances, or worsening of existing health conditions.

The importance of self-care during this time is essential in helping you cope with the daily updates regarding the current state of affairs regarding COVID-19. Things you can do include disconnecting from tv, radio, newspaper, and social media, as continuously hearing about the pandemic can be upsetting. Find time for joy - do things you enjoy and that make you smile and laugh (watch a funny movie, read a funny book, make crafts). Nourish your body - eat nutritious meals, get adequate amounts of sleep but not too much (6-8 hours per night), stay hydrated with water, and exercise regularly (meditate, stretch, yoga,). Stay connected - call friends, video chat, or go old school and make a phone call! Make yourself proud - make use of the time to get things done around the house that you have always wanted to do like clean out a closet, rearrange a room, or go through the catch-all drawer in the kitchen.

The most important part of coping with COVID-19 is to ensure you have accurate information. Seek information from credible websites, such as *CDC.gov* or *WHO.int*. The State of Illinois has created a website at *CORONAVIRUS.ILLINOIS.gov* for the latest updates around the state. For more information regarding mental health resources for coping with a crisis refer to *SAMHSA.gov*.

The ALS Association Greater Chicago Chapter will continue to be available to support you as well by moving all support groups to an online format at the regularly scheduled group times as well as offering virtual home visits through the same online platform as the support groups. If you are interested in a virtual home visit or have any questions, please reach out to your care service coordinator.

If you have any individual questions or concerns you would like to further discuss regarding depression, anxiety, or other mental health concerns, please feel free to contact me *Kellie E. Branch-Dircks, MSW, LCSW at kellie@alsachicago.org or 309-696-7184.*

The ALS Association Greater Chicago Chapter -- Chicagoland | Northern Illinois | Central Illinois

ALS Support Groups

Persons living with ALS, their family members, friends and caregivers are welcome to attend our support groups. **For the month of April, support groups will be held virtual-only** via Zoom video conference calls. Please contact the staff coordinator with questions.

Aurora, Wesley United Methodist Church
14 N May St, Aurora, IL 60506
First Saturday of Every Month, 10:30am - 12pm
Video Call-In: zoom.us/j/206738239
Call-In: 1-312-626-6799; Meeting ID: 206 738 239
Contact Gema for more info: gema@alsachicago.org

Orland Park, Faith United Methodist Church
15101 S 80th Ave. Room 18, Orland Park, IL 60462
First Thursday of Every Month, 4:00pm - 5:30pm
Video Call-In: zoom.us/j/495362901
Call-In: 1-312-626-6799; Meeting ID: 495 362 901
Contact Gema for more info: gema@alsachicago.org

Champaign

Champaign Public Library | Robeson Pavilion, Room C
200 W Green St, Champaign, IL 61820
Second Monday of Every Month, 1pm - 3pm
Video Call-In: zoom.us/j/280862102
Call-In: 1-312-626-6799; Meeting ID: 280 862 102
Contact Kellie for more info: kellie@alsachicago.org

Quad Cities | Bettendorf, IA

Unity Point Trinity Hospital | Conference Room A/B
4480 Utica Ridge Rd, Bettendorf, IA 52722
Second Monday of Every Other Month
6pm - 7:30pm
Contact Kellie for more info: kellie@alsachicago.org

Peoria

Fondulac District Library
400 Richland St, Room 112, East Peoria, IL 61611
Second Thursday of Every Month, 6pm - 8pm
Video Call-In: zoom.us/j/913836735
Call-In: 1-312-626-6799; Meeting ID: 913 836 735
Contact Kellie for more info: kellie@alsachicago.org



Glenview, Glenview Public Library
1930 Glenview Rd, Glenview, IL 60025
Second Saturday of Every Month, 10:30am - 12pm
Video Call-In: zoom.us/j/4334639988
Call-In: 1-646-558-8656; Meeting ID: 433 463 9988
Contact Peggy for more info: peggy@alsachicago.org

North Riverside, North Riverside Public Library
2400 Des Plaines Ave, North Riverside, IL 60546
Third Saturday of Every Month, 10:30am - 12pm
Video Call-In: zoom.us/j/422596742
Call In: 1-312-626-6799; Meeting ID: 422 596 742
Contact Audrey for more info: audrey@alsachicago.org

Rockford

Our Saviors Lutheran Church
3300 Corbridge Ln, Rockford, IL 61107
Fourth Tuesday of Every Month, 6pm - 7:30pm
Video Call-In: zoom.us/j/4334639988
Call-In: 1-646-558-8656; Meeting ID: 4334639988
Contact Peggy for more info: peggy@alsachicago.org

Stages of Grief

Jennifer Beckman, LCSW, CSW-G



While the grief journey of each individual is different, stages of grief were identified by psychiatrist Elisabeth Kübler-Ross in 1969 and have become known as the “five stages of grief.” These stages of grief were based on her studies of the feelings of patients facing terminal illness, but many people have generalized them to other types of negative life changes and losses.

It may be comforting to know that if you are experiencing any of these emotions that your reaction is natural. However, not everyone who grieves goes through all of these stages—and that’s okay. Some people may resolve their grief without going through any of these stages, while some may experience some stages but not all. If you do go through these stages of grief, you probably won’t experience them in a neat, sequential order, so don’t worry about what you “should” be feeling or which stage you’re supposed to be in.

The emotions that we feel while we are grieving can feel as though emotions come and go. You may find yourself feeling well and then without warning a rush of sadness may overcome you. Like waves or a roller coaster, the ride tends to be rougher in the beginning, the lows may be deeper and longer. The difficult periods should become less intense and shorter as time goes by, but it takes time to work through a loss. Even years after a loss, especially at special events such as a family wedding or the birth of a child, we may still experience a strong sense of grief.

While grieving a loss is an inevitable part of life, there are ways to help cope with the pain, come to terms with your grief, and eventually, find a way to move forward.

- Acknowledge your pain.
- Accept that grief can trigger many different, unexpected emotions and allow yourself to feel that emotion.
- Understand that your grieving process will be unique to you.
- Seek out face-to-face support from people who care about you.
- Support yourself emotionally by taking care of yourself physically.

Recognize the difference between grief and depression.

If you feel that you may benefit from extra support during the grief process, ask your Care Services Coordinator for additional support through The ALS Association.

For questions regarding additional support, please reach out to *Jennifer Beckman, LCSW, CSW-G, 309-261-7052 or jennifer@alsachicago.org*.

The above information was obtained from The 5 Stages of Grief at www.grief.com.

The five stages of grief:

DENIAL: “This can’t be happening to me.”

ANGER: “Why is this happening? Who is to blame?”

BARGAINING: “Make this not happen, and in return I will ____.”

DEPRESSION: “I’m too sad to do anything.”

ACCEPTANCE: “I’m at peace with what happened.”



Always Loved and Supported

This is a specialized program to support those who have lost a loved one to ALS. The program is focused on helping those bereaved to cope with their loneliness, how to understand their new roles, and healing ways to manage their emotional pain. We host a virtual meeting on the fourth Wednesday of every month from 7:00pm to 8:30pm. You may access the virtual group using this link zoom.us/j/677190871. You will need to initially download the Zoom video conference via this website: zoom.us (sign up is free).

For questions regarding the program, please reach out to *Jennifer Beckman, LCSW, CSW-G, 309-261-7052 or jennifer@alsachicago.org*.

2020 Public Policy Priorities and The ALS Association's Virtual Fly-In

Julie Sharpe, President and CEO

On March 25th, ALS Association Chapter Executives from across the country held more than 250 virtual meetings with members of Congress as part of the Association's annual "fly-in." I spent the day advocating for legislation and policies that will improve the lives of individuals living with ALS and fund research toward treatments and a cure.

Chief among the concerns of ALS advocates is making sure that legislation being drafted in response to the pandemic includes protections for people living with ALS and their caregivers, including protecting access to noninvasive ventilators and making sure people with ALS are not forced to wait five months to access Social Security Disability Insurance.

To learn more about 2020 Public Policy Priorities, visit: alsa.org/advocacy/Public-Policy-Priorities.html

If you want to become a virtual advocate, sign up today in just a few clicks. You'll receive periodic email updates and help to create emails and tweets about current ALS policies. Register: alsa.quorum.us/register/.

Julie Sharpe, President and CEO, julie@alsachicago.org



Development Corner

May is ALS Awareness Month!

Here are ideas to spread ALS Awareness while practicing physical distancing....

- **BEAUTIFUL DAY IN THE NEIGHBORHOOD:** leave a message in your window or on your driveway with sidewalk chalk. Participate in a neighborhood scavenger hunt with an ALS related clue or the Heart Hunters movement (decorating your windows with hearts for passersby during physical distancing) using our colors of red, black, and gold.
- **PLANT SEEDS OF HOPE:** our chapter symbol of the sunflower symbolizes our hope and strength, now as much as ever. Incorporate sunflowers in your online posts, in your crafty hobbies, or plant some sunflowers to enjoy this season.
- **GET SOCIAL:** share your passion and commitment to finding a cure for ALS with social media tools. Add a temporary Facebook profile frame, post a photo relating to your ALS hero or journey, and tell people WHY it's time for treatments and a cure. Follow our social media pages all month long for prompts and posts at @ALSChicago on Facebook, Twitter, and Instagram.
- **INVOLVE THE WHOLE FAMILY:** May 19th is ALS Youth Action Day! We are looking for all young go-getters who are doing projects large and small. Learn more at www.alsyouthchallenge.org.
- **HOST A DIY EVENT:** Use your creativity to make your own fundraiser that benefits the ALS Association Greater Chicago Chapter and spreads awareness.



Show your neighbors some love and spread ALS Awareness



Do you have plans for ALS Awareness Month? We'd love to hear them! To share your May projects, brainstorm ways to make your ideas come to life, or share a photo of your dog just for fun, you can contact Sam Courter at samantha@alsachicago.org.



Run to Defeat ALS

26.2 Miles through the Streets of Chicago to Fight ALS!

We will have our largest TeamALS to date, with 165 charity runners participating in the 2020 Bank of America Chicago Marathon. These amazing folks signed on for an incredible challenge – to raise both awareness and funds to help in the fight against ALS while training to run 26.2 miles on October 11, 2020. These great people are coming from all across the US, as well as a few from Canada and the UK. We are in awe of their dedication to the cause and to see all they are already doing. So far, they have raised \$50,000 for ALS care and research. You may read more about their personal stories via their fundraising pages at web.alsa.org/TeamALS2020. We look forward to seeing all they continue to do on their marathon journeys as they Run to Defeat ALS!

For volunteer opportunities or to learn more about the 2020 Marathon, email Run Coordinator [Sarah Brandt](mailto:sarah@alsachicago.org) at sarah@alsachicago.org.



Walk to Defeat ALS

In an uncertain time, one thing is certain...we will continue to plan for our largest support groups of the year...also known as The Walk to Defeat ALS. We know how much you look forward to these events each year and we are going to do everything we can to give you an amazing experience! If you are in Chicagoland, I urge you to register at web.alsa.org/chicagowalk. No matter what our Chicago Walk on June 6th looks like, we need all the superheroes we can get to combat this disease!!

While our Chicago Kick-Off went virtual, we are hopeful our Fall Walk Kick-Offs (held in late June) will be in person! Speaking of our Fall Walks, we invite you to take part in our:



PEORIA WALK

September 12th
Dozer Park, Peoria
web.alsa.org/peoriawalk



NORTHERN ILLINOIS WALK

September 19th
LOCATION CHANGE TBD!!
web.alsa.org/northernil



CENTRAL ILLINOIS WALK

September 26th
Dodds Park, Champaign
web.alsa.org/champaignwalk

Sponsorship opportunities are currently available for all walks...for more information, please contact [Kendra Albers at kendra@alsachicago.org](mailto:kendra@alsachicago.org).



The ALS Classic

Cog Hill Golf & Country Club | September 9th, 2020
Presented by The Hartford

Please join us for a day of golf and fun to support our mission cornerstones of care, advocacy, research, and awareness for the ALS Community.



Chicago Auto Show's First Look for Charity

Our Chapter was one of 18 non-profits to partner with this prestigious Chicago event. This black-tie gala kicks off the Chicago Auto Show as a preview night with special access to view the vehicles, sample food and beverages from local Chicago establishments, and listen to some great live music, all while benefiting charity. This unique event did not disappoint, and it was a true honor to be part of this phenomenal evening. We welcomed our ALS supporters for a VIP experience in the Iron Horse Suite prior to the main event. Then everyone joined the party to mingle and celebrate raising a combined \$2.8 million for charity through this one night!

We are grateful for all those who supported ALS through this event, and we are very much looking forward to participating again in 2021!



Staff Highlight

Our newest addition to the team is Administrative Coordinator, Jessica Leeseberg, who started in October of 2019. Get to know Jessica, who you may hear from when you call the office or register for an event or program!

How did you get initially involved with the ALS Association? Two years after my Grandmother died of ALS, my family and I stumbled across the Chicago Walk to Defeat ALS and saw that it was in our backyard. We created Team Marlene in her memory and walk to remember her.

What is your favorite part of your role? My Grandmother was my favorite person to talk to and every time I get to talk with and help a patient or their family it feels like I'm helping her. And that makes me happy.

What are your favorite hobbies? Crocheting, Reading, and catching up with friends.

What books are you taking to a desert island? *The Book of Lost Things* by John Connolly, Louise Penny's Inspector Gamache Series, and *Who Moved my Cheese?*

What's your message to our chapter members? Thank you for welcoming me with open arms into your lives and letting me be a part of your support system. It is an honor and a privilege to help you in whatever capacity I can.

Need to update your contact information with the Chapter? Jessica would love to help at 312.932.0000 or jessica@alsachicago.org!



Volunteer with The ALS Association Greater Chicago Chapter!

We can't do what we do without YOU!

Our group of volunteers, Lou's Crew, are the backbone of our Chapter. Lou's Crew has continued to grow over the years, and we are so thankful for each and every member of this group. From help with event planning and participation, to light clerical work, we would not be able to do it if not for Lou's Crew. We are always looking to add to the ranks! People of all abilities are encouraged to join us. Are you interested in joining?

Visit bit.ly/ALSChicagoVolunteer or contact Sarah at sarah@alsachicago.org and 312-932-0000.



Our Ambassador Program continues to grow as more individuals are stepping up to deepen their commitment to end ALS. Welcome our newest Ambassadors – Brian Laesch, Michelle Hansen, Sarah Martin, Susan Fralick, and Meredith Lindgren.

Due to the current CDC guidelines, we had to reinvent our Spring in-person meeting to a virtual event! While things may be changing, the passion our Ambassadors have to fight back against ALS and ensure the individuals we serve are getting the best support they can, doesn't waver. Over the next month, our Ambassadors will be making outreach to individuals living with ALS to check in. Additionally, donors and team captains can expect outreach as well!

If you have anyone you would like to nominate to be an Ambassador, please email [Kendra Albers at kendra@alsachicago.org](mailto:kendra@alsachicago.org).

The ALS Association Greater Chicago Team



Julie M. Sharpe
President and CEO
2006 - Present
julie@alsachicago.org



Joumana Barood, RN, BSN
Director of Care Services
2010 - Present
joumana@alsachicago.org



Kendra Albers
Director of Development
2015 - Present
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Peggy O'Connor, RN, BSN
Care Service Coordinator
2015 - Present
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Sarah Brandt
Volunteer Coordinator
Run to Defeat Program Coordinator
2012 - Present
sarah@alsachicago.org



Audrey Scafidi, LPN
Care Services Coordinator
2014 - Present
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Samantha Courter
Fundraising and Marketing
Coordinator
2019 - Present
samantha@alsachicago.org



Kellie Branch-Dircks, MSW, LCSW
Care Services Coordinator
2014 - Present
kellie@alsachicago.org



Jessica Leeseberg
Administrative Coordinator
2019 - Present
jessica@alsachicago.org



Gema Ramos, RN
Care Services Coordinator
2016 - Present
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Jennifer Beckman, LCSW
Care Services Coordinator
Social Worker
2018 - Present
jennifer@alsachicago.org



Kaveri Bhatnagar, MA, CCC-SLP
Speech Language Pathologist
2014 - Present
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Stephanie Barb, CCC - SLP
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