

# The ALS Association Greater Chicago Chapter Care Services Support Newsletter Fall 2019

## 2019 Educational and Scientific Symposium

*Joumana Baroodi, RN, BSN, Director of Care Services*



The ALS Association Greater Chicago Chapter's 9th annual patient and caregiver Educational and Scientific Symposium will be held on Wednesday, October 23rd, 2019.

The event is an opportunity for individuals living with ALS, caregivers, and advocates to learn more about research, treatments, and management of ALS. The Vendor and Service Provider Expo allows attendees to engage with long-term community partners of the Greater Chicago Chapter who understand ALS-specific needs and can provide durable medical equipment and services to the ALS Community.

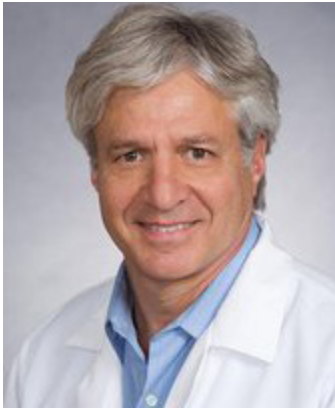
The "Ask the Experts Panel" will take place during the lunch program, featuring four experts in the field. Leading this panel is Neil Thakur, Ph.D, Executive Vice President for Mission Strategy at The ALS Association. Dr. Thakur leads The ALS Association's nationwide advocacy, care services, and research programs. Prior to joining the Association, Dr. Thakur served in the National Institutes of Health (NIH) Office of the Director, where he supported NIH governance and helped make NIH research more open and less burdensome. He managed the world's largest policy to make biomedical research papers publicly accessible, co-chaired the White House task force that lead to the requirement that all federal science agencies adopt similar policies, and spent a year on detail to the US Senate. Dr. Thakur has worked with health systems in many capacities, including serving as Assistant Director of Health Services Research and Development at the Department of Veterans Affairs (VA), and working in and researching behavioral health systems across the country.



*Neil Thakur, Ph.D.*

Panelist John Ravits, MD, is a board certified clinical neurologist specializing in amyotrophic lateral sclerosis (ALS), motor neuron diseases, neuromuscular disorders, and clinical neurophysiology. Dr. Ravits is the director of the ALS clinic at UC San Diego Health and vice chair of adult neurology and the neurological sciences. Dr. Ravits is on the editorial board of the medical journal Amyotrophic





*John Ravits, MD*

Lateral Sclerosis & Frontotemporal Degeneration. He serves on the scientific advisory committee of the Muscular Dystrophy Foundation, and also serves on the steering committee for the World Federation of Neurology Research Group on Motor Neuron Diseases.

Chris Zallek, MD is a neuromuscular disorders specialist at the OSF HealthCare Illinois Neurological Institute and Clinical Assistant Professor of Neurology at the University of Illinois College of Medicine - Peoria. He is the neuro health investigator at Jump Simulation Center. His interests are focused on neurological exam training simulators, quantification of the neurological exam by technology, and the means of technologies to improve the neurology health care delivery model. Dr. Zallek earned his medical degree at the University of Iowa where he also served his internship. He completed his neurology residency and neuromuscular disorders/EMG fellowship at the University of Michigan.



*Chris Zallek, MD*

Michael Robinson, Ph.D., graduated medical school from Queen's University in Kingston, Ontario, Canada. He did his internship at the University of Toronto and completed residency training in both Child & Adolescent Psychiatry and Adult Psychiatry at Queen's University. Dr. Robinson subsequently completed fellowship training in Psychosomatic Medicine at Virginia Commonwealth University/Medical College of Virginia. Dr. Robinson returned to Queen's University as an Associate Professor of Consultation-Liaison Psychiatry where his clinical practice focused on patients with HIV or hepatitis C, and his research focused on psychopharmacology in the medically ill as well as delirium.

Dr. Robinson joined the Pharmaceutical Industry at Eli Lilly and Company where he held a number of positions working in drug development and commercialization in the therapeutic areas of Psychiatry and Pain. He then transitioned to AbbVie as a Vice President, where he initially lead the development of Therapeutic Area Medical Teams around the world. Dr. Robinson then lead the development of a dedicated US Medical Affairs team where he lead a team of over 400 scientists and physicians involving therapeutic areas including Neuroscience, Hepatology, Immunology, Oncology, Endocrinology, and Women's Health. Dr. Robinson retired from Abbvie in 2016 after being diagnosed with ALS.



*Michael Robinson,  
Ph.D.*

*Joumana Baroodi, RN, BSN, Director Care Services  
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*2018 Educational and Scientific Symposium*

We hope you will join us, and we look forward to seeing you on Wednesday October 23rd, 2019. To register for the event please visit: [bit.ly/gccsymposium2019](https://bit.ly/gccsymposium2019) or call the office at 312-932-0000.

## Research News

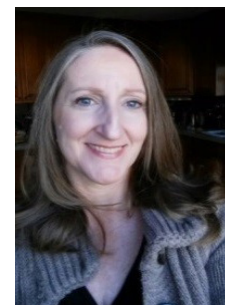
The University of Chicago ALS clinic will soon start enrolling patients with ALS as a part of HEALEY ALS Platform Trial. Healey platform trial is a collaborative effort at several sites across the U.S., led by Massachusetts General Hospital, to perform multiple clinical trials at a rather short period of time. Trial design also decreases the chance of patients receiving a placebo in the Healey platform trial. Please contact Dr. Rezania ([krezania@uchicago.edu](mailto:krezania@uchicago.edu)) the principal investigator, or Shail Bhatnagar ([sbhatnagar@neurology.bsd.uchicago.edu](mailto:sbhatnagar@neurology.bsd.uchicago.edu)) if you are considering participation in this trial.



## The Importance of Multidisciplinary Care in ALS Management

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

The Oxford dictionary defines multidisciplinary as “combining or involving several academic disciplines or professional specializations in an approach to a topic or problem.” Because ALS affects so many aspects of one’s health and function, it requires specialized management and coordination from a variety of disciplines. Care involving visits to a multidisciplinary ALS center is the current standard of care for people living with ALS.



### A multidisciplinary ALS team is made up of:

- *Neurologist*: a physician specializing in diagnosis and management of disease of the nerves
- *Pulmonologist*: a physician specializing in diagnosis and management of disease of the lungs
- *Physical therapist*, who assesses and helps maximize mobility and function with the use of appropriate exercise, adaptive devices and equipment, or bracing



- *Occupational therapist*, who assesses and helps maximize independence in activities of daily living, such as eating, dressing and bathing, through activity modification, specialize exercises, bracing or adaptive devices
- *Speech and Language pathologist*, who maximizes function of swallowing with compensatory techniques, and speech through adaptive strategies or augmentative means
- *Dietitian*, who helps develop an appropriate and individualized plan to prevent weight loss and maintain adequate nutrition
- *Social Worker*, who assesses psychosocial needs and connects patients and families with resources to effectively meet these needs
- *Nurse*, who provides ongoing education and coordination of the many aspects of ALS management

Additional specialties such as gastroenterology and palliative care also work closely with multidisciplinary ALS clinic teams to help provide comprehensive care.

Patients are seen in an ALS clinic approximately every three months, and the visits can be quite time-consuming. These long, tiring visits may seem counter-intuitive when we speak so often of the importance of energy conservation in ALS. When we step back and look more closely at this model of care, we see that it makes a great deal of logical sense, and is backed by research.

Although multidisciplinary care in ALS is the current standard, this was not always the case. It was only relatively recently that the importance of coordinated care across specialties was well studied and documented. In 1999, the American Academy of Neurology (AAN) developed evidence-based practice parameters for neurologists caring for ALS patients. These recommendations supported some essential principles in ALS management, including a high priority placed on self-determination and autonomy, and allowing patients to be active participants in decisions regarding their care. It was stressed that information regarding treatment options be made available well in advance of the time of decision-making, and that the care provided be comprehensive, and delivered with compassion and empathy.

These parameters were updated in 2009 to further document and emphasize the benefit of multidisciplinary care. These updated parameters also addressed behavioral and cognitive changes that may be seen in ALS, and to encourage ongoing research into all aspects of clinical care in ALS.

### **The benefits of attending a multidisciplinary clinic include:**

*Access to expert care and increased disease knowledge* – ALS is a rare disease, one with which many healthcare practitioners have little or no experience. Attendees at multidisciplinary clinics benefit from one-on-one assessment and individualized care planning with ALS experts in each of their respective disciplines. The providers are very knowledgeable in ALS care, and share this information with the patient with every interaction.

*Improvement in survival* – Respiratory and nutritional status in particular are closely monitored at

multidisciplinary ALS clinics, and changes are addressed promptly. This leads to increased and earlier utilization of interventions such as PEG, NIV, and airway clearance, which in turn leads to longer disease survival.

*Reduction of ER visits* – The close and frequent monitoring of patients in a clinic setting allows timely response to any issues that arise. Care is proactive and preventative in nature, rather than reactive. This results in fewer emergency situations.

*Reduced cost* – Decreased use of unnecessary tests and procedures, as well as decreased use of emergency services, reduce cost.

*Reduced travel burden, streamlined care* – Rather than making multiple trips to a medical center to meet with various specialists, patients can attend a “one-stop-shop” and benefit from the evaluation by multiple disciplines in one visit. In a multidisciplinary setting, practitioners collaborate and are in regular communication, resulting in comprehensive and streamlined care.

*Improved quality of life* - Access to quality care that conforms to best practices, appropriate disease education, proactive management of symptoms, and autonomy in decision-making contribute to improved quality of life.

The ALS Association Greater Chicago Chapter is proud to support multidisciplinary care in our affiliated ALS clinics across Illinois. In partnering with these exceptional clinic teams, we strive to bring the best care available to those living with ALS.

*Peggy O'Connor, RN, BSN, Care Services Coordinator,  
The ALS Association Greater Chicago Chapter, [peggy@alsachicago.org](mailto:peggy@alsachicago.org)*

## Knowledge is Power

*Joumana Barody, RN, BSN, Director of Care Services*

Receiving the diagnosis of ALS may trigger a wide range of emotions, including fear, anger, loss, sadness, and depression. Questions about coping, living fully, interacting with loved ones, and preparing for the future will certainly arise.

Coping with the ALS diagnosis is a very individual process. Everyone responds differently. There is no right or wrong way to feel when you learn your diagnosis. It is important to remember that it does not mean you cannot have a life; it means that you need to go about your life differently and make adjustments. Many people with ALS have suggested that it helps to maintain a positive, determined and optimistic attitude.



When you learn you have ALS, you also learn there is no cure and effective treatments are still in development. However, much has changed in the care and treatment of ALS and there have been important advancements in understanding the disease and helping to manage it, despite having no cure at this time.

With the fast advancement of scientific technology and neurological research, there is more hope now than ever before that more and better treatment options will be available. These facts give hope, but it is essential to achieve a balance between hope and realistic expectations. Empower yourself by learning everything you can about ALS and how it will affect you.

## Use Trusted Sources for Information

Following the diagnosis of ALS, most people start searching for information from various sources. It is important to find trusted sources, some of which are listed here:

- Go to the local library or bookstore and search for medical books about ALS.
- A multitude of information is available at our fingertips on the World Wide Web. The Internet can be an excellent source of health-related information, but you should be careful. It is important to educate yourself and carefully assess the content of websites.
- Watch out for any site selling a product, a service, a treatment or a therapy and making glowing claims about its successes, as in promising to cure an illness(es) or disease(s).
- Be wary of treatments or therapy claims of a “cure” and “fast”. If it sounds too good to be true, it probably is.
- Be skeptical about a treatment or a therapy that relies solely on personal testimonials rather than research findings reported in a reputable medical or scientific journal.

You should also remember that not all websites can be trusted. To evaluate the validity of a health website, look for these important characteristics:

1. The purpose of the website should be clearly stated.
2. The authors of the material must be identified. Look for the authors’ credentials. Is the author a physician, nurse or other health care professional?
3. The owner of the website and the organization with which the author is affiliated should be identified with contact information.
4. Beware of health websites that appear to be trying to sell something.
5. If the website quotes material from another source, the appropriate credit should be given.
6. The date of publication should be clearly posted. Make sure the information you are reading is current.
7. The website should have a clearly stated privacy and security policy, especially if you are disclosing personal information.

Aside from health websites, there are a number of other forums for receiving health information on the web:

- Bulletin boards: Threaded discussions that involve health-related postings from participants
- List serves: A compilation of postings that are forwarded to subscribed participants
- Social media: Twitter feeds or Facebook pages where people convene to share information
- Chat rooms and Forums: Live discussion among participants, usually related to a specific medical topic.

These forums can provide a wealth of helpful information, ideas and support. However, be wary of the information that is generated. Some information might be based on personal opinions, or even worse, be displayed for the sole purpose of selling a product.

Look for reputable and reliable health-related websites:\*

- The ALS Association (National website) [www.alsa.org](http://www.alsa.org)
- Your local ALS Association Chapter [www.alsachicago.org](http://www.alsachicago.org)
- ALS Association Certified Treatment Centers of Excellence [www.alsa.org](http://www.alsa.org) › community › centers-clinics
- The National Institute of Neurological Disorders and Stroke (NINDS) [www.ninds.nih.gov](http://www.ninds.nih.gov)
- The National Institutes of Health (NIH) [www.nih.gov](http://www.nih.gov)
- Centers for Disease Control (CDC) [www.cdc.gov](http://www.cdc.gov)
- National Organization for Rare Diseases (NORD) [www.rarediseases.org](http://www.rarediseases.org)
- Northeast ALS Consortium (NEALS) [www.neals.org](http://www.neals.org)
- WebMD [www.webmd.com](http://www.webmd.com)
- Health Finder [healthfinder.gov](http://healthfinder.gov)
- Mayo Clinic [www.mayoclinic.org](http://www.mayoclinic.org)
- Health on the Net Foundation [www.hon.ch](http://www.hon.ch)
- ALS Untangled [www.alsuntangled.com](http://www.alsuntangled.com) offers a scientific review of alternative treatment options.
- You can also find information about clinical trials by going to [www.clinicaltrials.gov](http://www.clinicaltrials.gov)

\*The ALS Association provides these links for informational purposes only. The Association does not endorse these web sites, nor any product or physician represented on these sites.

The Internet has become a valuable tool to give and receive information. As long as you can balance what you hear with the regular consultation of your physician or other medical professional, you can increase your knowledge with both efficiency and confidence.

Another great source of information is achieved by attending ALS Association Educational Symposia. Please join us at the upcoming 9th Annual Educational & Scientific Symposium and Luncheon featuring an “Ask the Experts Panel”, hosted by The ALS Association Greater Chicago Chapter, on Wednesday October 23rd. This event is designed to educate and inform those living with ALS, their families, caregivers, and allied health professionals, of any update in ALS research and treatment.

Details of this event is in the article titled “2019 Educational & Scientific Symposium and Luncheon” on page one of this newsletter.

#### *Disclaimer*

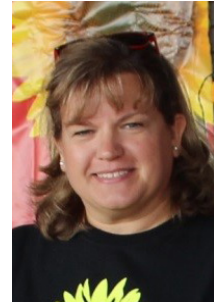
*This information has been written by Joumana Baroody, RN, BSN, Director Care Services, The ALS Association Greater Chicago Chapter, and/or copied from various sources, (ALS Association Publication, Internet, Articles). The information is intended to be general in nature and is not to be relied upon as medical advice. Before any action is taken relative to your specific situation, you should check with your physician.*

*Joumana Baroody, RN, BSN, Director Care Services, The ALS Association Greater Chicago Chapter, [joumana@alsachicago.org](mailto:joumana@alsachicago.org)*

## Keeping it Real with Kellie in Central Illinois

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

Summer has ended and the wonderful fall sights and smells are upon us. We had two amazing walks in Peoria and Champaign, with both communities making their voices heard to celebrate those they love diagnosed with ALS as well as wanting an end to ALS today! Support groups in both regions have had good attendance, but many families have not been able to attend due to vacations and making memories with family and friends. We are still working on formalizing the clinic in Peoria, IL, but several patients have started attending clinic in Peoria and report positive experiences.



Coming up this fall we have the Caregiver Boot Camp on November 16th, right here in Central Illinois, and I encourage everyone who is a family or friend caregiver to attend. It is close, free, and incredibly beneficial in helping you know how to care for your loved one as they live with ALS. December support groups will be our annual Christmas parties, and as always, there will be AMAZING prizes, snacks, and memories to be made!

### Medical Information Updates

With the cold winter months coming, this is a good time to review your medical packets, update information, and check supplies, including:

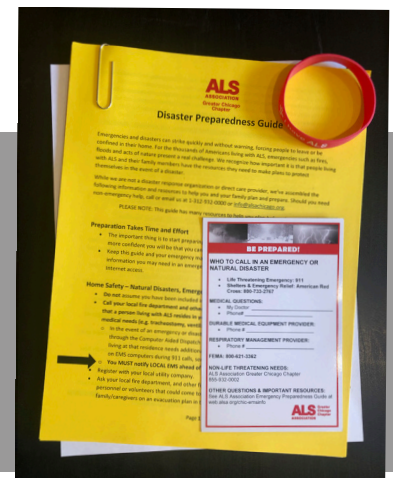
- Healthcare Power of Attorney Forms
- POLST
- Medication lists
- Emergency contact lists and phone numbers
- Physicians and contact details
- Check your generators (if you have one)
- Flashlight batteries

If there are weather emergencies, we will do our best to reach out to patients and their families on Facebook/Twitter/Instagram with guidance of shelters and emergency info as we obtain directives. Staff will reach out to patients in impacted areas after the imminent emergencies are over. Please remember we are not an emergency response service but will do what we can support patients and families impacted by weather emergencies once a crisis is stabilized by first responders.

*Kellie Branch Dircks, MSW, LCSW, Care Services Coordinator,  
The ALS Association Greater Chicago Chapter, [kellie@alsachicago.org](mailto:kellie@alsachicago.org)*

## Emergency Kit

The ALS Association Greater Chicago Chapter provides kits to individuals living with ALS to help with planning for an emergency situation while living with the disease. If you would like an emergency kit or an updated copy, please contact your Care Service Coordinator.





*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. The groups are an opportunity to meet others, learn about new information and resources, and provide or receive support and encouragement. Guest speakers attend some of our support groups, and talk about their area of expertise as it relates to individuals living with ALS.

For more information, please contact a member of our Care Services Team. RSVPs are highly recommended. You may RSVP through our Calendar of Events on our website or by contacting a member of the Care Services Team.

### **Aurora**

Wesley United  
Methodist Church  
14 N May St, Aurora, IL 60506  
First Saturday of every month  
10:30am - 12:00pm  
Contact Gema for more info:  
gema@alsachicago.org

### **Champaign \* NEW LOCATION FOR 2019\***

Champaign Public Library  
Robeson Pavilion, Room C  
200 W Green St  
Champaign, IL 61820  
Second Monday of every month  
1:00pm - 3:00pm  
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  
6:00pm - 7:30pm  
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 - 12:00pm  
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 - 12:00pm  
Contact Audrey for more info:  
audrey@alsachicago.org

### **Orland Park**

Faith United Methodist Church  
15101 S 80th Ave, Room 14,  
Orland Park, IL 60462  
First Thursday of every month  
4:00pm - 5:30pm  
Contact Gema for more info:  
gema@alsachicago.org

### **Peoria**

#### **\*NEW LOCATION FOR 2019\***

Fondulac District Library  
400 Richland St, Room 112,  
East Peoria, IL 61611  
Second Thursday of  
every month  
6:00pm - 8:00pm  
Contact Kellie for more info:  
kellie@alsachicago.org

### **Rockford**

Our Saviors Lutheran Church  
3300 Corbridge Ln  
Rockford, IL 61107  
Fourth Tuesday of every month  
6:00pm - 7:30pm  
Contact Peggy for more info:  
peggy@alsachicago.org

***Not all  
superheroes  
wear capes.  
Hug a hero of  
yours today!***

## Flu and Pneumonia Vaccines for ALS

*Gema Ramos, RN, Care Services Coordinator*

As the season changes to cooler weather, the prevalence of the flu (influenza) also emerges. According to the Centers for Disease Control and Prevention (CDC), the flu is a contagious disease usually transmitted through sneezing, coughing and close contact. The common symptoms of the flu are a sudden onset of fever, muscle aches and pains, fatigue and headache. People with ALS often experience a wide variety of challenges related to weakened swallowing and respiratory muscles, including difficulty managing saliva, coughing and clearing secretions. With a cold or the flu, the challenges in dealing with ALS are magnified with fatigue, thick mucus, cough, dehydration, and fever.



People with ALS are also prone to developing pneumonia since the weakness in the swallowing muscles can allow food or liquids to get in the lungs. Pneumonia is an infection of the lungs with common symptoms of fever and chills, cough, rapid breathing or difficulty breathing, and chest pain. As a first line of defense, prevention is important. People with ALS should do everything they can to avoid any respiratory infections by getting the annual flu vaccine and the pneumococcal vaccine.

### References:

[www.alsa.org/als-care/living-with-als/flu-season.html](http://www.alsa.org/als-care/living-with-als/flu-season.html)

[www.alsa.org/als-care/resources/publications-videos/factsheets/flu.html](http://www.alsa.org/als-care/resources/publications-videos/factsheets/flu.html)

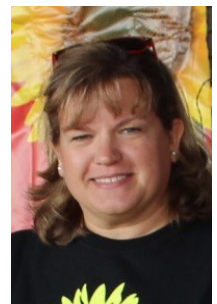
*Gema Ramos, RN, Care Services Coordinator, The ALS Association Greater Chicago Chapter,  
[gema@alsachicago.org](mailto:gema@alsachicago.org)*

## Emotional Experiences of Being a Caregiver

*Kellie Branch Dircks, MSW, LCSW, Central Illinois Care Service Coordinator*

**“You gain strength, courage, and confidence by every experience in which you really stop to look fear in the face. You must do the things which you think you cannot do.” — Eleanor Roosevelt**

The road to becoming a caregiver in the world of ALS takes a different journey for everyone, but the common route for everyone involved is that it is a road no one ever wanted to have to take. Throughout your journey, many emotions will surface, some of which you may be reluctant or embarrassed to admit, for fear of being judged or being a burden to others. The problem is...the struggle is REAL! If you don't acknowledge ALL of your emotions related to being a caregiver, the Good and the Bad, the emotions will tug at you and force you to take note in others ways: poor



sleep, illness, trouble coping, stress eating, substance abuse, etc. When you admit to your feelings, you can then find productive ways to express them and deal with them, so that you and the care receiver can cope better in the future.

## **Ambivalence**

This is the feeling of both wanting to be doing what you are doing and the feeling of not wanting to be doing it. On bad days, one often has the feeling of wishing you didn't have to be there, that this ordeal will be over soon. On good days, caring for someone can be a gift to both you and the care receiver.

*Coping:* Allow yourself to feel both sets of feelings. Everyone has these feelings sometimes. Neither the bad feelings nor the good ones will last forever.

## **Anger**

How often have you “lost it” while providing care? Or felt like you were on your last nerve? Anger and frustration are a normal part of being around someone who needs help on an ongoing basis and who might not be accepting of help. Caring for someone with ALS with frontal temporal dementia, in particular, can be even harder, as the care receiver can be irrational and combative. It's not always possible to be in perfect control of your emotions. Anger “just comes out” sometimes.

*Coping:* Forgive yourself. Find constructive ways to express yourself, learn to walk away and give yourself a “time out.” Identify supportive people you can talk to who will listen as you vent about the things that happened that day.

## **Anxiety**

Feeling like things are out of control and not knowing how to bring them back into control often produces feelings of anxiousness. Anxiety can emerge as a short fuse, the impulse to run away, not sleeping, heart palpitations, or the urge to cry.

*Coping:* Pay attention to your anxiety—it is our body's early warning system that something isn't right. When you feel anxious: Stop. Breathe. Keep breathing. Pray. Meditate. Make some tea. Anything that will give you a break from what is happening in the moment.

## **Boredom**

It is easy to become bored when you are stuck at home taking care of someone else and not doing things that fulfill your own wants and needs. And by the end of the day, you are often too tired to pursue something of interest to you.

*Coping:* Respite can help. Getting a break from caregiving and having some time for yourself will not only increase your patience and resilience but will give you a chance to do something that is meaningful to you, whether it is socializing, going for a walk, or reading a good book.

## **Crankiness, Irritability**

When tired and stressed, it is harder to stay in control of the things we say and feel. Feelings can go up and down very rapidly. We can lash out at the slightest thing because we have no reserve.

*Coping:* If you find yourself feeling cranky and irritable, you probably need a break. You also may need to get some rest, as we are in less control when tired. Often we will turn to alcohol or our favorite junk food to reward ourselves when feeling this way. It's more beneficial to keep a journal or talk with a friend or professional to let off steam.

## **Depression/Sadness**

As a caregiver, you are at risk for depression. Sometimes this is feeling hopeless or helpless, the inability to sleep, or trouble getting up and facing the day. And sometimes it makes you want to cry.

*Coping:* Depression is treatable and should be taken seriously. Professional help is available. Talk to your physician if you think you might be depressed, join a caregiver support group, find a counselor who understands caregiving, and ask for help from friends and family. Exercise. Moving your body is a proven way to relieve some of the symptoms of depression.

## **Disgust**

Having to help toilet someone can be too intimate an experience for many caregivers. If the care receiver is incontinent of stool as well as urine, then changing an adult diaper can be nauseating and repulsive. Having to clean the private body parts of someone, like a parent, can be unnerving and uncomfortable. Watching someone eat sloppily or not care for personal appearance, or having to clean up vomit can also cause feelings of disgust.

*Coping:* The hardest thing about accepting our revulsion to these things is that the care receiver is not in control of these behaviors. But sometimes we think they are doing it on purpose just to get to us. Or we feel guilty because we think we should be accepting but we are not. Finding ways to minimize your need to do personal care tasks including incontinence care is vital to weathering your caregiver journey, which could stretch on for years. Hire an attendant to do routine care or have someone from the family do these things who might cope better. Also, learn tricks to make tasks easier.

## **Embarrassment**

Does your care receiver make impolite comments when you are out in public? Does he or she need to use the restroom right away and make a scene as you try to find one? Does he or she refuse to bathe and now have body odor? It is easy for us to feel responsible for the behavior of someone else and feel like it is our fault when these things happen.

*Coping:* Have friends, family members, or an attendant accompany you when they go out to offer assistance, when needed.

## **Fear**

What if something happens? Will I be able to cope? Will I feel guilty? Am I responsible for things that go wrong? Caregivers take on a huge amount of responsibility, not only for the day to day care of the care receiver, but also for all the other things that “might” happen while being a caregiver. Scaring ourselves about the “what ifs” can be paralyzing and keep us from enjoying the “what is.”

*Coping:* It is important to have contingency plans. So, it might make sense to have a back up caregiver in mind in case something should happen to you, or to think about how you would handle predictable medical emergencies based on what disabilities your care receiver has. When you get scared, it is often helpful to talk to someone who knows your situation and can give you perspective and calm your fears.

## **Frustration**

Frustration is part of many other feelings, such as ambivalence, anger, and impatience. Sometimes, as a caregiver, you feel that you can't do anything right or that things just don't go as planned no



matter what you do or how hard you try. And if you are tired, you are more likely to get frustrated. Frustration may lead to stress eating, substance abuse, and a higher likelihood of losing your temper. *Coping:* Acknowledge how frustrating caregiving can be. Join a support group to learn the tricks other caregivers have learned to make coping easier. Get breaks from caregiving so you have time for YOU and a chance to refresh your energy. Exercise. Sleep.

## Grief

Watching the care receiver decline, not being able to do things that used to be easy and natural is sad. We also grieve for the care receiver, the person who used to be and our relationship with that person. We often need to grieve the loss we are experiencing on a daily basis or it will come out as something else.

*Coping:* Sometimes creating a ritual can be helpful. One caregiver would write on a piece of paper the things her husband could no longer do, then go to the ocean and throw the pieces in the water as a way of letting go. We tend to want to avoid the sadness that comes with grief, but allowing ourselves to feel it promotes healing.

## Guilt

Guilt is the feeling we have when we do something wrong. Guilt in caring for care receivers comes in many forms. There is guilt over not having done enough to have prevented them from getting sick in the first place. There is guilt over feeling like you want this to end. Or guilt over having been impatient with your care receiver too often. There is guilt over not loving or even liking the care receiver at times. There is guilt over not doing enough for the care receiver or not doing a good enough job as a caregiver. And if the care receiver falls or something else happens, there is guilt about it being your fault that it happened. And sometimes caregivers feel guilty about thinking of their own needs and see themselves as selfish, especially if they should do something like go to a movie or out to lunch with a friend.

*Coping:* You need permission to forgive yourself. You can't be perfect 24/7. It's impossible to be in perfect control of how you feel at all times. We all carry around a lot of "shoulds," such as "no one will do as good of a job as I do, so I have to be here all the time" or "If I leave and something happens, I will never forgive myself." Consider changing guilt into regret, "I'm in a difficult situation and I have to make difficult decisions sometimes." "I regret that I am human and get impatient sometimes." "I am doing the best I can even though things go wrong from time to time and I regret that I am not perfect."

## Impatience

How difficult is it to get your care receiver up in the morning? How about up, dressed, given breakfast and to their doctor's appointment all before 10:00a.m.? And you have other things to accomplish that day. All this and the care receiver is acting unhelpful and moving slowly. Perhaps the care receiver refuses to use his walker even though he has fallen many times and the doctor and physical therapist have emphasized he always needs to use it. It is understandable that you would get impatient at times.

*Coping:* Forgive yourself. When tired, frustrated, and trying to keep things under control, it's natural to want to speed up and have compliance from the care receiver to keep them safe and healthy. So, first, slow down. Leave a lot of time to accomplish tasks. Leave a LOT of time. Control the environment as much as you can, but know you can't always prevent your father from taking off

without his walker. Create a list of the things you are in control of and are not. Understand what you can and cannot control.

## **Jealousy**

Do you sometimes feel jealous of your friends who are able to go out and do things that you can no longer do, because of your caregiving responsibilities? Are you jealous of your siblings who are not doing their share to help? Do you feel jealous of a friend whose parent died quickly and easily while you take care of a parent who has had dementia for many years? Are we jealous of someone who got a big inheritance since we are struggling to pay bills and to be a good caregiver? We often don't admit to this feeling, because we have always been told not to be jealous. But that doesn't mean that we don't, in fact, feel jealous from time to time, of those who have it easier or better than us.

*Coping:* It's okay to admit to being jealous. Because things are not fair, we often have flashes of resentment and envy at other people's good fortune compared to our own. Jealousy is a problem when we wallow in it and prevent ourselves from enjoying the things we DO have. Focus on what you do have, whatever that may be, and find a place in your heart for gratitude.

## **Lack of Appreciation**

Most of us do not want to be dependent on someone else. Learning to accept help is hard. So, the care receiver is often pushing away our attempts to be helpful and caring. If someone has dementia, this problem is often much worse. And we get our feelings hurt because the care receiver does not thank us or even see how much we are giving up in order to care for them.

*Coping:* Sometimes we have to give ourselves our own pat on the back. Writing in a journal about the things you do each day might help you to appreciate how much you give and how much you do. Having a support group or a group of friends/family to cheer you on is important, and both comforting and necessary to remain resilient through your caregiving journey.

## **Loneliness**

The longer you are a caregiver, the more isolated you become. With no one to talk to day in and day out except the care receiver, it is easy to lose a sense of yourself. Friends stop calling since we are no longer available and we hesitate to call them because we know "they don't want to hear about it any more" or "I have nothing to talk about because my life is all about caregiving."

*Coping:* Find ways to get out of the house and involved in something other than caregiving. Learn about resources from your local Area Agency on Aging about respite programs or day care programs that will allow you to get a much-needed and well-deserved break. No one can do this job alone. Look at your wider circle of support—faith community, neighbors, friends, distant relatives, etc. to see where you might get some nurturing for you.

## **Loss**

Caregivers experience many losses, some of which have already been mentioned: loss of control, loss of independence, loss of income, loss of your best friend, loss of the future, loss of a sense of yourself. Loss leads to grief and depression.

*Coping:* Identifying your losses can help you to cope with them. For each of us, the losses will be different. When you know what you are feeling, you will be able to look at the loss and think about what might work for you to help you deal with it.

## Resentment

When put in a situation not of our choosing, it's not uncommon to feel negative and resentful. Perhaps you have siblings who are not helping provide care or maybe you are an only child, became the caregiver by default, and feel you have very little desire or support to offer care. Little things easily become big things when we feel unappreciated and unacknowledged. And feeling like you have to do it all, and do it all by yourself, is a guaranteed way to feel resentment.

*Coping:* Family situations and dynamics can be a real challenge. Having help from family may make your situation easier, but sometimes family tensions make it even harder to get help. The more help and support you accept, the easier it will be to let go of feeling burdened and resentful of those who are not doing their share. If family tensions are getting in the way, it could also help you Holding a Family Meeting. If you can't get help from the people you think should be offering it, then you need to broaden your circle of people to include those who can and will help. It is easy to forget about the good things that have happened or are happening when we only focus on the negative.

## Tiredness

As a caregiver, how often do you get the full eight hours of sleep they always say you need? Sleep is often postponed while you grab a few minutes of alone time after the care receiver goes to bed. Sleep is often disturbed because the care receiver gets up at night and needs help going to the bathroom or being re-directed back to bed. Sleep is often disturbed because you can't fall asleep or stay asleep because you are worrying about all the stressors that come with being a caregiver.

*Coping:* Sleep has to be put on the priority list. Lack of sleep leads to obesity, illness, crankiness, impatience, inefficiency in accomplishing tasks, and a state of mental fogginess among other issues. If you are having trouble falling asleep or staying asleep not related to direct caregiving, talk to your physician. If you are having trouble sleeping due to caregiving problems, talk to the care receiver's physician. There are ways to help both of you to get the rest you need. As a caregiver, you do amazing work caring for others in need. But as a caregiver, you also need to think about yourself. Just pushing through each day will eventually wear you out and cause you to burn out. Emotional issues can weigh you down and impact not only your ability to cope and provide care, but they can also harm your health and well-being. It is important to learn to ask for help and prioritize getting breaks from caregiving, so that you can be the caregiver you want to be.

The above information was obtained from Family Caregiver Alliance National Center on Caregiving Website: [www.caregiver.org](http://www.caregiver.org)

Your ALS Association Care Service Coordinator is always available to help guide you regarding resources for your individual needs as well. The Chapter also offers an on-line counseling as well as an on-line grief support group for as well. The ALS Association Chicago website has a variety a resources that can answer many of the questions you may be struggling with in the form of written communication and video. Caregiving is an honor yet a challenge at the same time. It is human to have mixed emotions regarding a role you were unexpectedly given, but remember, you are not doing this alone. The ALS Association is here to help you and your loved one in your journey.

*Kellie Branch Dircks, MSW, LCSW, Care Services Coordinator,  
ALS Association Greater Chicago Chapter, [kellie@alsachicago.org](mailto:kellie@alsachicago.org)*

## Remembering a Loved One During the Holidays

Jennifer Beckman, LCSW, CSW-G



The temperature has dropped and the leaves are starting to change colors. Fall is here which means that the holidays are right around the corner. As much as the holidays can bring joy and happiness, the holidays can also bring sadness as grief can come like a wave with no warning. For most of us, it is much easier to use avoidance and denial as a way to cope during the holidays, however

I propose a different approach of keeping your loved one's memory alive by continuing to make them a part of your holiday traditions.

There are many different ways to honor your loved one during the holidays, here are a few ideas to get you started:

*Light a candle* – Designate a special candle that you light during the holidays, especially on the days when you find yourself missing your loved one the most.

*Reminisce with your family* - share stories of your loved one with your family and friends and encourage them to share.

*Display an old photo* - Frame your favorite picture of your loved one display it near your family gathering.

*Set a spot at the table*- set a place setting for your loved one at the dinner table (This would also be a great spot for the candle and photo)

*Watch old videos* – bring out the old videos of your loved one to watch with your family. Although this may be emotional, you may be comforted by seeing your loved one on TV. It could also open the door to reminisce with your friends and family.

*Donate to a cause* – Donate to your loved one's favorite charity or to the ALS Association Greater Chicago Chapter in honor of your loved one.



### 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](https://zoom.us/j/677190871)**

You will need to initially download the Zoom video conference via this website:

**[zoom.us](https://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](mailto:jennifer@alsachicago.org)**



**Volunteer** – Volunteer your time in honor of your loved one. Was your loved one a veteran? Donate your time at a local VFW. Did your loved one love animals? Spend some time at a local animal shelter or donate food and other needed items.

**Christmas Ornament** – Buy or make a special memorial ornament to display every year in honor of your loved one.

**Be kind to yourself** – Most importantly, you must take care of yourself. It is okay to say no to an event. Reach out for help/support if you feel the need. Attend a support group. Seek out individual counseling in your community. 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](mailto:jennifer@alsachicago.org).



## Caregiver Boot Camp

### Saturday, November 16th

### Davis Lodge, Hudson, IL

Please join us for the Central Illinois Caregiver Boot Camp on Saturday, November 16th, 2019 from 10:00am until 2:00pm. The Caregiver Boot Camp will provide education about the role of a Caregiver, how to use common pieces of medical equipment, and provide an opportunity to ask questions to better prepare for assisting a loved one living with ALS.

The event is FREE and lunch is provided. For more information and to RSVP, please email Kellie Branch Dircks at [kellie@alsachicago.org](mailto:kellie@alsachicago.org) or call 312-932-0000.



## Development Corner



THE ALS ASSOCIATION GREATER CHICAGO CHAPTER, OFFICIAL CHARITY PARTNER  
INVITES YOU TO SAVE THE DATE FOR

# CHICAGO AUTO SHOW'S FIRST LOOK FOR CHARITY

FRIDAY,  
FEBRUARY 7,  
**2020**

MCCORMICK PLACE  
2301 S KING DR,  
CHICAGO, IL 60616  
★ ★ ★ ★  
IRON HORSE VIP SUITE

**7:00**  
IN THE EVENING  
BLACK TIE

Learn more and purchase your ticket at  
<http://bit.ly/firstlookals>



## The Iron Horse Rally to Defeat ALS

Thank you to everyone who participated, volunteered, and helped plan the 2019 Iron Horse Rally to Defeat ALS! We had a great day generating awareness for the ALS Community. The day consisted of a 60-mile ride which took off from the Fox-River Harley Davidson and ended at the Batavia VFW. Rainy weather couldn't dampen our spirits as we rode to defeat ALS.





## Journeying Together

One of the new faces at the Iron Horse Rally was Viola Vlasak, 92, who was diagnosed with ALS in January of 2019. After a few sleepless nights after her diagnosis, Viola made up a bucket list. One big item on that list: a return trip to Disney World. Viola, her husband, and their young children first walked through the gates in April of 1974.

In addition to the Disney trip, Viola took a ride on her son's 2006 Harley Ultra Classic through the Florida neighborhood. Viola describes her son Rich Vlasak, as a "super son and really good guy. He calls me every day. He reminds me of my appointments." Rich has been riding since he was a child--minibikes, dirt bikes, small street bikes and two Harleys over the years.

To get Viola ready for a safe and fun ride, Rich and a neighbor helped Viola get secured into the bike. Rich said "The Ultra Classic is a great bike for a passenger in that was kind of locked in with back rest, arms and a little music. My neighbor, a retired police officer, help with lifting mom over the bike and into the seat. It would have been very hard for her to swing her leg over."

During the ride, Viola smiled and waved to the neighbors as they went by. She found it exciting and fun, but her favorite part was being with Rich. When asked how she would describe traveling by motorcycle to others who haven't before, Viola described it as "a feeling of complete freedom."

The trip to Disney was a smashing success! Viola, her now grown children, and her grandchildren enjoyed a visit to Disney World. Viola went on Small World and Seven Dwarves Mine Train. She's still working on her bucket list and her advice to others living with ALS is: "Just keep living, don't shut yourself away from the world."



*Top: 2019 Iron Horse Rally, Middle: Viola and Rich, Bottom: Disney World Trip*







## The ALS Classic

### Thankful \*Fore\* Another Wonderful Outing

Over 160 golfers gathered at Cog Hill Golf & Country Club in Lemont on Wednesday, September 4th for the 13th annual ALS Classic Golf Outing. We welcomed wonderful golf weather and enjoyed spending the time together. Thank you to all sponsors, golfers, and volunteers for making the day a success.

For more information, please contact Julie at [julie@alsachicago.org](mailto:julie@alsachicago.org) or 312-932-0000.



## Run to Defeat ALS

### 26.2 Miles through the Streets of Chicago to Fight ALS!

After months of training and preparation, the day will soon be here! 2019 will be the 10th year that TeamALS will be represented at the Bank of America Chicago Marathon. This year we have the largest number of runners to date, with 150 bibs raising funds and awareness for ALS. Congratulations to each runner for their dedication and hard work. Over \$300,000 has already been raised by the team for research and care.

If you'll be at the Marathon, please help us cheer on TeamALS. You can also learn more about the teams and runners at the TeamALS website.

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







## Walk to Defeat ALS

September was a busy month for our Walk teams, volunteers, and participants. Three superhero-themed events were held throughout the Chapter in Peoria, Rockford, and Champaign. Thank you to the many, many superheroes who made the days so special. Each day was full of connection and showing support for the patients and families battling ALS in our Chapter. While the events are over, we're not quite done with our super year: the websites will remain open until November 30th.



### Peoria: 9/7

We welcomed over 550 new and returning walkers representing 33 teams to Dozer Park for a sunny morning in Peoria full of superhero fun.  
[web.alsa.org/peoriawalk](http://web.alsa.org/peoriawalk)



### Rockford: 9/21

Rockford has raised over \$81,000 to date by nearly 400 participants. The weather may have been rainy but we were all sunny smiles as we walked Rock Valley College in support of families battling ALS in Northern Illinois.

[web.alsa.org/rockfordwalk](http://web.alsa.org/rockfordwalk)



### Champaign: 9/28

Early morning rain turned into beautifully cloudy and bright skies as 17 teams were represented by over 300 participants at the third annual Champaign Walk to Defeat ALS at our new location of Dodds Park.

[web.alsa.org/champaignwalk](http://web.alsa.org/champaignwalk)

While in the midst of connecting with our super walkers in Central and Northern Illinois, we were also thrilled to see the thermometer for the Chicago Walk meet and SURPASS its 2019 fundraising goal. Thank you to everyone who took part in raising \$596,911 for advocacy, research, and care for families battling ALS in our Chapter.

**“WE DID IT!! Our Chapter’s Greater Chicago walk raised over the goal that we had set for this year!**

**Your help with this fundraising effort provides critical support of our mission, which is to discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest. As donors to our Chapter, you are a part of our community and you make everything we do possible.” - Joumana Barood**

## ALS Disability Insurance Access Act: October Collaborative Push for Cosponsors

With congressional attention moving away from appropriations, now is the time to continue to build upon the momentum we've built over the last seven months for the ALS Disability Insurance Access Act. Currently, the bill is supported by 50 senators and 193 representatives. In order for the legislation to continue to move, we need to gain as much support as possible.

### Take Action: Urge Congress to Support the Bill

Send a letter to members of Congress, either asking them to cosponsor or thanking them for their support. Find a template letter to Congress available in our Advocacy Action Center at [alsa.quorum.us/campaign/ssdi/](https://alsa.quorum.us/campaign/ssdi/)

Reach out on social media. Example Social Media Messages:

*Time works against people living with #ALS and current laws require those diagnosed to wait five full months before they receive their Social Security Disability Insurance (SSDI) benefits. Tell Congress to eliminate this waiting period: [alsa.quorum.us/campaign/ssdi/](https://alsa.quorum.us/campaign/ssdi/) #ALSAdvocacy*

*Currently, people diagnosed with #ALS are required to wait five full months before they receive their Social Security Disability Insurance benefits. Tell Congress to eliminate this waiting period: [alsa.quorum.us/campaign/ssdi/](https://alsa.quorum.us/campaign/ssdi/) #ALSAdvocacy*



## 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](https://bit.ly/ALSChicagoVolunteer) or contact Sarah at [sarah@alsachicago.org](mailto:sarah@alsachicago.org) and 312-932-0000.





## Do it Yourself (DIY) Fundraising

DIY Fundraising is a chance for individuals or groups to host their own fundraising activity that benefits The ALS Association Greater Chicago Chapter. The Greater Chicago Chapter will provide the tools, but the DIY part offers the flexibility to manage fundraising activities based on individual interests, schedules and budgets! The activity – whatever that may be – will raise awareness and needed funds to directly impact the ALS Community.

Rockford Walk to Defeat ALS Team SuperDave recently completed their first team fundraiser: a night of live music and raffles at a local bar. Co-captain Joe played piano and sang, while attendees could buy raffle tickets for prizes or a 50/50 drawing. The team also held a “loose change war” where participants added coins to a jar to vote on someone to take the Ice Bucket Challenge. The bar also donated 10% of their profits from the evening. Co-captain Julie talked to us about the experience.

What was your favorite part of hosting a DIY Fundraiser?: *Seeing the final result! Seeing all of the planning turn into a fantastic event.*

What is your advice for someone who wants to plan their first DIY Fundraiser event?: *Teamwork!! Our team each contributed ideas and energy to make our fundraiser work, having different people in charge of different things (decor, advertising, activities, supplies, etc.) made it not too overwhelming for just one person to do.*

If you'd like to host a DIY Fundraiser, please contact Samantha at [samantha@alsachicago.org](mailto:samantha@alsachicago.org) or 312-932-0000 to get started today!



**ALS**  
ASSOCIATION  
Greater Chicago  
Chapter  
*Ambassador*



Our ALS Ambassadors are key volunteers who have demonstrated commitment to the Chapter by their involvement in multiple capacities with passion for our mission and the people that we serve. They have worked tirelessly and enthusiastically to raise both awareness and funds, and advocate on behalf of the Greater Chicago Chapter.

Visit [bit.ly/ALSChicagoVolunteer](http://bit.ly/ALSChicagoVolunteer) or contact Sarah at [kendra@alsachicago.org](mailto:kendra@alsachicago.org) and 312-932-0000.

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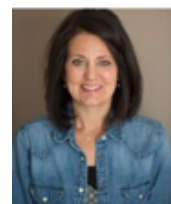
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