



NEWSLETTER

FOR & ABOUT CAREGIVERS

CAREGIVER CONNECTIONS

MARCH/APRIL 2021

Resources for Caregivers



AphasiaAccess is an organization that empowers professionals in the field of aphasia to share knowledge and research with one another, to pool resources and to serve as a learning community in order to improve the care of, and access to treatment for, people with aphasia and their families. To that end, AphasiaAccess has begun distributing a monthly resource to professionals. Included below are links to aphasia friendly materials that may help in broaching potentially difficult to discuss topics with your family member with aphasia. These materials were created by the Stroke & Aphasia Recovery (STAR) Program at Texas Tech University Health Sciences Center in collaboration with the Aphasia Center of West Texas. They were made using ParticiPics from the Aphasia Institute in Toronto, Canada, and Google clip art. Clicking on the link below will take you to the document which you can download to your computer and print out.

[Communicating with a Person with Aphasia \(click here\)](#)

[Visiting the Doctor \(click here\)](#)

[Medical Decision Making \(click here\)](#)

[Dealing with Depression \(click here\)](#)

[Dealing with Anxiety \(click here\)](#)

One of the goals of the Adler Aphasia Center's newsletter is to connect our many caregivers who live across the New York-New Jersey metropolitan region who may not be able to attend the Center's caregiver support groups.

We hope to share suggestions for self-care, information about community resources, developments in aphasia knowledge, relevant medical advances, as well as caregiver happenings at the Adler Aphasia Center.

We welcome feedback, ideas, and suggestions. Please email your comments to Tamara Heimlich, PhD, Life Coach at Adler Aphasia Center at theimlich@adleraphasiacenter.org.

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SOMETHING SPECIAL

MEMBER BLOG





NURSING HOME RATING SYSTEM HIDES PROBLEMS

On March 13th, 2021, The New York Times (nytimes.com) published its investigation into how the star program run by the U.S. Centers for Medicare and Medicaid (CMS) that rates American nursing homes has been manipulated to disguise multiple, and often severe problems. More than 15,000 nursing homes participate in the ratings program.

Nursing home ratings range from one star (the lowest rating) to five stars (the highest rating) and are based on three components:

- in-person inspections conducted by state health inspectors
- the staffing score, based on self-reported data about how much time nurses spend with patients
- self-reported data about the quality-of-care patients receive, assessed in 15 areas, including the number and types of medications residents take, and the number of wounds, such as bed sores

The findings from their exhaustive review of more than 350,000 reports by state inspectors and the financial reports submitted by more than 10,000 nursing homes include the following:

- Between 2017-2019, health inspectors cited more than 5,700 nursing homes for misrepresenting data about residents' well-being, including more than 800 facilities with high ratings
- Even when these discrepancies were found, audits were not conducted to verify other self-reported data

- Multiple studies found serious underreporting by nursing homes in particular areas, including:

1. The percentage of falls residents had that required hospitalization
2. The percentage of incidents where residents were hospitalized because of possible neglect or abuse in their nursing home
3. The percentage of residents who developed deadly bed sores

- Many nursing homes reported inflated staffing hours by including the hours of administrative nurses, rather than those of only registered nurses who provide direct care to residents. CMS permits this reporting, but the public sees only the total number of hours and not a breakdown in hours between the types of nursing staff
- The use of antipsychotic drugs, sometimes dangerous for older people, and opioid pain medications, have often been underreported
- Additional issues include top rated nursing homes that failed to report violence or abuse; these incidents did not affect their five-star ratings
- Even though nursing home inspections can take place any time, in 2019 approximately 70% of nursing homes increased their staffing on days that inspectors visited, suggesting that administrators had advance notice about the visits. The article states that inspection day was the best staffed day for more

than 800 homes, increasing by an average of 25 staff hours.

- Finally, the report notes that during the Covid-19 pandemic, nursing home ratings had very little to no correlation with the death rates in nursing homes. Homes with five stars had a half a percentage point lower death rate than homes with fewer stars, and two-star homes had a slightly lower death rate than four-star homes.

It is evident that relying only on the number of stars a home is rated is not sufficient to make an informed decision about where you or a family member should live. It is vital for family members to ask specific and direct questions about staffing, the turnover rate

of nurses and nursing assistants, the types of social programming, the frequency of doctor's visits, and the use of psychiatric medications to manage behavior. Whenever possible, a physical tour to see the condition of the residents, the manner in which staff members interact with them, and the cleanliness of the facility, is also a crucial component when making this important decision for your loved one or yourself, whether for long-term care or short-term rehabilitation. ■



Sleep Please!

Sleep is restorative and is crucial for our well-being. Many adults in the United States are chronically sleep deprived, and over-taxed caregivers may find it especially difficult to turn off their worries and fall asleep or stay asleep. Elizabeth Bernstein reports (WSJ.com, March 23, 2021) that 40% of the population has had sleep problems during the pandemic. The heightened stress, anxiety, loneliness, and isolation of the pandemic have all contributed to this increased incidence of sleep issues.

People with chronic insomnia are those who have difficulty falling asleep or staying asleep three times a week for a month or longer, leading to fatigue, mood changes, or difficulty concentrating during the day. Worrying about not being able to sleep also often contributes to insomnia.

Bernstein outlines several strategies in order to increase the amount of time we spend in bed sleeping (our sleep efficiency):

- Practice good sleep hygiene – although seven to nine hours of sleep may seem unrealistic, aim for as

many hours in this window as possible; avoid alcohol, caffeine, and exercise before bed; turn off cell phones and computers 30-60 minutes before bed

- Only go to bed when you are sleepy
- If you have difficulty falling asleep, get out of bed and read, listen to music or do another calming activity in a different room. The blue light from electronic devices will keep you awake so it is best not to use them
- Wake up the same time every day to help regulate the body's circadian rhythm; sleeping late one day will make it harder to fall asleep that night
- Try not to worry about sleeping, or about having difficulty functioning the next day in the event you do not get sufficient sleep; as noted above, the worry will make it more difficult to fall asleep
- If you have many concerns, write them down in a journal during the day to decrease the likelihood you will think about them while trying to fall asleep
- Think about what you are grateful for in order to associate pleasant thoughts with going to sleep
- Cognitive behavioral therapy for insomnia (CBT-I) that includes some of the above suggestions may be indicated to help retrain the brain and improve sleep efficiency. The Department of Veterans Affairs offers a free online course, and the Cleveland Clinic offers a six-week online course for a fee. There are also smartphone apps to aid with sleep. For more information about CBT-I and how to improve your sleep, you can go to www.sleepfoundation.org. ■



pre-stroke identities, their rebuilding processes, and their emotional journeys.

Interestingly, Adler staff noted that when medical residents visit Adler's Advocacy group to learn from our members with aphasia, the doctors' only experience of people with aphasia has been in the immediate aftermath of stroke; the doctors have never met people with aphasia who are in the process of rebuilding their lives. Adler staff also noted that the very nature of the Center's group structure encourages members to share their struggles with each other, resulting in their receiving significant emotional support from one another.

Ask Adler

On Thursday, April 1st, 14 Adler Aphasia Center staff members joined in conversation over Zoom with the Co-Founders of Stroke Onward, Debra Meyerson, her husband, Steve Zuckerman, and Program Director, Jodi Kravitz. Stroke Onward was founded as an outgrowth of Dr. Meyerson's book, *Identity Theft: Rediscovering Ourselves after Stroke*. Dr. Meyerson, whose work as a professor at Stanford University focused on diversity and identity, is a multi-stroke survivor and has aphasia. As noted on its website, the mission of Stroke Onward is to "provide stroke survivors, families and caregivers with more resources to help them navigate the emotional journey to rebuild their identities and rewarding lives."

Stroke Onward is reaching out to the aphasia community to better understand where the emotional journey fits in the work of aphasia centers, individual speech-language therapy, and academia, and how this young organization can be a resource to us in our work. Based on Dr. Meyerson's struggle to find emotional support during her recovery, she also offered suggestions for increased training in coaching, counseling, and grieving in SLP degree programs and in continuing education courses. Furthermore, she encouraged and empowered Adler staff to talk more often with our members about the loss of their

One of Stroke Onward's primary goals is addressing the emotional journey in aphasia and stroke recovery and elevating it to be on par with the physical and communication journeys, already addressed by physical, occupational, and speech therapies. In order to accomplish this goal, Stroke Onward hopes to influence both health delivery systems and educational systems. Bringing greater awareness to the professional community and stroke survivors alike about rebuilding identity post-stroke is an important first step in this process. Dr. Meyerson and her husband write a periodic column about their family's journey and experiences for the [American Stroke Association](#). To find out even more about Stroke Onward's groundbreaking work, [click here](#). ■

This newsletter is produced by Tamara Heimlich, PhD. Tamara is a Life Coach and Research Associate at the Adler Aphasia Center. Tamara received her BA in psychology from McGill University in Montreal, and her MA and PhD in Clinical Health Psychology from Yeshiva University. She completed her predoctoral internship in the Department of Rehabilitation Medicine at Mount Sinai Medical Center. She also served as the research coordinator for the Comprehensive Epilepsy Center at NYU Medical Center, working primarily on the Multicenter Study of Epilepsy Surgery. Tamara joined the Adler Aphasia Center as a volunteer in 2009, and later, in 2013, as an employee, assuming the role of research associate. In 2017, Tamara began offering life coaching sessions for members and caregivers, and later curated a speaker series to address the unique needs of the Center's caregivers.

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Adler Aphasia Center, a non-profit organization with three full service facilities based in Maywood, West Orange, and Toms River, NJ and eleven Communication Groups located throughout the state, is an innovative post-rehabilitative therapeutic program that addresses the long-term needs of people with aphasia and their families. Aphasia is a communication disorder that impairs the expression and understanding of spoken language, reading and writing. It occurs most often from a stroke or other brain injury. It affects a person's ability to communicate, but not his or her intellect. For more information about our programs and services in Maywood, West Orange or Toms River, NJ, or for information about our Aphasia Communication Groups in Belvidere, Bridgewater, Haddonfield, Hammonton, Maywood, Monroe, Morristown, North Bergen, Scotch Plains and Toms River, NJ, visit our website at www.adleraphasiacenter.org or call 20.368.8585.