

# Together, let's make healthy happen. AdvocateAuroraHealth

### Letter from the Medical Director - Darren Gitelman, MD, FAAN, FANA

Dear patients, friends, families, and colleagues of the Advocate Memory Center:



"When I was a boy and I would see scary things in the news, my mother would say to me, 'Look for the helpers. You will always find people who are helping." -Fred Rogers.

Welcome to the second edition of the quarterly Advocate Memory Center e-newsletter! We appreciate the positive feedback we received from our inaugural newsletter and are pleased to stay connected with you in this way. The Advocate Memory Center continues to be fully operational throughout the COVID-19 pandemic. Since our last update, we have resumed in-person clinic visits, when necessary, in order to provide the best care for our patients. Our highest priority is the safety of our patients, families, and associates. In alignment with the Advocate Aurora

<u>Safe Care Promise</u>, we are taking additional measures to protect all who enter our clinic. We also continue to offer telehealth services.

In this newsletter, we introduce you to two new staff members at the Center, Dr. Anthony McCormack and Carl Fransman, RN. Both bring a wealth of experience to the Center that will help to enhance the care provided to our patients. In future newsletters we will introduce other team members.

The cognitive symptoms of Alzheimer's disease, such as memory loss, are well known, but equally important are the behavioral symptoms of the disease. These behavioral symptoms can create even more disability when they appear, and can be particularly distressing for both patients and caregivers. In this issue of the newsletter, we discuss a non-medication approach to evaluating and treating these symptoms, which can be used by families and caregivers.

A new section of the newsletter this edition is the Resource Corner. This section will provide links to valuable planning resources. One of the most difficult aspects of dementia is that it interferes with a patient's ability to make choices as the disease advances. Certainly, one of the most important choices is how someone wants to be medically treated at all stages of life, and who will make medical and financial decisions for them when they are no longer able to do so. Therefore, in this edition we focus on Advance Care Planning.

We have also included sections on activities supported by the Center, upcoming events, clinical research trials, and our clinical support programs

Finally, I want to comment on two issues affecting our patients and our nation. First, the COVID-19 pandemic is continuing unabated, and has recently worsened in many parts of the country. Both the disease, and the social distancing to avoid it, have taken a heavy toll on seniors and those with Alzheimer's disease and other forms of dementia. COVID-19 has also been particularly hard on Black and Latinx communities. While we wait for a vaccine and other new treatments to be developed, there are ways now to reduce the impact of COVID-19 on ourselves, on our families, and on our communities. Although there remain many questions about this virus, the science on prevention is clear: Wear a mask; practice social distancing; quarantine yourself if you've been potentially exposed, and wash your

<u>hands</u>. Please see the COVID-19 section of this newsletter for more information and resources.

Second, the pervasiveness and toll of racism, starkly highlighted over the past few months, also represents a pandemic. Medicine is unfortunately no stranger to racial discrimination, and progress to remedy the disparities in healthcare between Caucasians and racial minorities has been too slow. As with many diseases, Alzheimer's disease and other dementias disproportionately affect Black and Latinx seniors. Advocate Aurora Health has been engaged in steps to reduce these disparities - from faith-health partnerships to community outreach initiatives, from associate recruitment strategies to team member diversity training - and recognizes the need to do more on both apersonal and organizational level. At the Memory Center, we too have undertaken efforts to reduce inequities, by providing both clinical services and educational programs in minority communities. We acknowledge the need to do more in this arena, echo Advocate Aurora Health's commitment to Diversity & Inclusion, and will continue to seek opportunities to examine both the biases in our care and ways to reduce bias in the future.

Thank you again for reading our newsletter,



Darren Gitelman, MD Director of Cognitive Disorders, Advocate Medical Group Senior Medical Director, Advocate Memory Center

# **Advocate Memory Center Staff Highlights**



**Dr. Anthony McCormack, MD** is a geriatrician and family practitioner who studied medicine at the University of Illinois at Chicago School of Medicine. He completed residency at MacNeal Family Medicine and fellowship training at LaGrange Memorial Hospital. He subsequently spent nearly 30 years as a primary care geriatrician. When the position at the Advocate Memory Center became available he decided to shift his practice to working with patient's primary care physicians, rather than being one himself, and to focus entirely on dementia care. In his prior work, Dr. McCormack, with the support of others, developed a

comprehensive geriatric care center that raised the standard of care in the community he served. He describes that his "life's work is to preserve health and help patients grow from the challenges that life presents so that individuals feel compelled to view life as a sacred unique gift..." He shares that what he most enjoys about his work is the "physician patient relationship" which he believes "fosters empathy, hope, and healing." He feels that it is "very rewarding and an honor to participate in this professional dedicated relationship." Dr. McCormack began his work with the Advocate Memory Center in July 2020. He is excited about joining a team who has, in his words, "developed a program that is bringing hope and compassionate care to patients, their families, and our health care community." In his spare time, Dr. McCormack loves to learn, and enjoys family-centered projects such as gardening, home life, art, and music. Please join us in welcoming Dr. McCormack to the Advocate Memory Center when you see him in the clinic. We are fortunate to add his experience and compassion to our team!



**Carl Fransman, RN** is a nurse who graduated from Trinity Christian College with a Bachelor of Science in Nursing. He joined the Advocate Memory Center team in May 2020. He assists patients and families in many ways including triaging calls, explaining test results, and obtaining prior authorization for procedures. Carl shares that he "always wanted to work at Advocate" because he "admires its strength and mission to help people." He entered the field of nursing because of his "fascination with the complexity of the body and the mind" and

his desire to help people in a "real hands-on way." He enjoys speaking with patients and their families to help them describe their symptoms so our team can best intervene. He describes his professional mission as being to "treat patients and their family members as I would a member of my family." In previous roles, Carl worked on a medical intensive care unit, served on a committee working on the best wound treatments, provided case management services, and supported patients and their families at the end of life. In his spare time, Carl enjoys spending time with family, gardening, watching movies, and exercising. He even completed the Chicago Marathon in 2004, and feels that since he survived that, he can survive anything! Please join us in welcoming Carl if you see him in the clinic or receive a call from him. We are thrilled to add his knowledge and his calm presence to our team.

# **Focus on Neuropsychiatric Symptoms**

While dementia is defined as a condition causing decline in cognition (e.g. memory, reasoning, language, or calculations), neuropsychiatric changes - such as agitation, irritability, apathy, disinhibition, and depression - arise in 98% of patients. These symptoms can be some of the most challenging for family caregivers and healthcare professionals to manage. In fact, the Alzheimer's Association reports in their 2019 Facts & Figures that the presence of four or more such symptoms is associated with a higher prevalence of "clinically meaningful depression and burden" in caregivers (p. 34). A variety of factors can converge to cause these symptoms, including the underlying neurological condition, acute medical issues such as a urinary tract infection, pre-existing or new mental health concerns, environmental characteristics, unmet needs, and caregiving approaches. And while medications are often used to treat these symptoms, and may be necessary in some cases, they may not be FDA-approved for this purpose and may carry significant risks. So how can we help individuals and their families find relief from these distressing symptoms? We will offer some general guidance and resources here, and in future newsletters you can look to this section for strategies to manage specific behavioral symptoms.

Neuropsychiatric symptoms - also known as the Behavioral and Psychiatric Symptoms of Dementia (BPSD) - can arise from a number of causes. As suggested by Kales et al. in outlining their <u>DICE approach</u> - Describe, Investigate, Create, Evaluate - understanding what gives rise to a particular behavior or symptom may be foundational to any successful intervention. The DICE approach, outlined below, provides a simple framework to identify and modify potential triggers for a behavior.

DESCRIBE the patient's behavior, statements, feelings, and any safety concerns; the caregiver's behavior, statements, feelings, and safety; and environmental factors such as other people present, time of day, and the activity in which the patient is engaged when the troubling behaviors occur.

INVESTIGATE factors in the patient (e.g. medication change, pain, fatigue, poor hearing / vision, emotional state, new medical problems), caregiver (e.g. knowledge of dementia, communication style, expectations of the patient), and environment (e.g. noise level, lighting, familiarity with the surroundings) that may have contributed to the behavior.

CREATE a plan to modify the potential triggers identified such as managing a patient's pain, ensuring the patient has sufficient rest, trying a new communication approach, checking for a urinary tract infection, or limiting excessive commotion in the environment.

EVALUATE if the above modifications were successful. Were there any unintended consequences?

These steps may have to be repeated to get at the root of the behavior, and it is encouraged to discuss the symptoms with the patient's healthcare team.

Here is one quick example of how a care team might implement this approach:

Barry, an 86-year-old man in the middle stages of Alzheimer's disease, has recently become agitated and restless.

DESCRIBE: Barry has begun pacing around the house and leaving his home unsupervised. He is agitated and angry, and yells that he needs to "get to work!" He swings at his wife, Rosie, when she tries to block him from leaving.

INVESTIGATE: Barry has not had any recent changes in his health or medications. However, he has been home 24/7 for four months, due to the pandemic. Previously, he had attended adult day services 5 days per week. Now, he has little activity aside from watching TV. His wife, Rosie, has been fearful about COVID-19. She has had the news on all day everyday, and keeps the TV at a high volume since she is hard-of-hearing. She worries that Barry will leave their house and she won't be able to keep up with him due to her lung disease.

CREATE: Barry's nurse practitioner, hearing the TV blaring in the background when talking to Rosie on the phone, suspects that the excessive noise is confusing and distressing for Barry. She also realizes, given that Barry's agitation began immediately after the statewide stay-at-home order, that he likely is missing the routine and activity of his day program (hence his demand to go to "work"). While talking with Rosie about pharmacological and non-pharmacological approaches to decrease Barry's agitation, she hears Rosie yell at Barry "You stopped working 25 years ago! Go help me pay the bills if you're looking for something to do!" Hearing this, the nurse practitioner realizes that Rosie has unrealistic expectations of Barry's abilities, and that the spouses' anxiety likely feeds off of each other.

The nurse practitioner suggests that Rosie could benefit from some respite, and Barry is likely to benefit from more structure and engagement. She suggests bringing in a companion to engage in activities with Barry several mornings each week. She places an order for an Occupational Therapy home safety assessment, for help making the home safer (e.g. alarms and a stop sign on the front door) and developing a daily routine. She also refers Rosie to the clinic social worker for education about ways she can communicate with Barry that might help calm him (e.g. "Work is closed today, Barry. Let's look at this photo album of your company's anniversary party and you can tell me more about how you built the company.").

EVALUATE: At Barry's follow-up video visit with the nurse practitioner, he and Rosie are both visibly calmer. He tells the nurse practitioner that he's been teaching his new companion about gardening. Rosie notes that he's also enjoyed looking through old photo albums and news articles about the company he built. Rosie has replaced her hearing aides so she can turn the volume down on the TV. The OT has helped them put up company pictures around the house, which has helped Barry feel "at home," and door alarms have eased Rosie's anxiety.

For more information on the DICE approach, visit: <a href="https://diceapproach.com/page/about">https://diceapproach.com/page/about</a>

To view short videos from dementia expert Teepa Snow, including a video regarding challenging behaviors, visit: <a href="https://teepasnow.com/resources/about-dementia/">https://teepasnow.com/resources/about-dementia/</a>

For more information on behavioral symptoms, visit the Alzheimer's Association at: <a href="https://www.alz.org/help-support/caregiving/stages-behaviors">https://www.alz.org/help-support/caregiving/stages-behaviors</a>

#### **Resource Corner: Advance Care Planning**

The COVID-19 pandemic has highlighted the importance of having conversations about, and documentation of, advance care plans, for all adults over age 18. Following are tools to help guide these discussions.

**Advance Directive for Dementia:** Created by internal medicine physician Barak Gaster, MD, this form provides education regarding symptoms and functioning during mild/moderate/severe stages of dementia and instructs the patient to choose a goal of care for each dementia stage - <a href="https://dementia-directive.org/">https://dementia-directive.org/</a>

**The Conversation Project**: Conversation Starter Kit designed to prepare loved ones of individuals with dementia to have discussions regarding care wishes. Includes a broad range of topics for discussion such as to what degree patient wants to be informed of her condition, preferred care setting, privacy concerns, and end-of-life treatment approaches -

https://theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-StarterKit-Alzheimers-English.pdf

**Center to Advance Palliative Care:** Toolkit for providers / healthcare professionals including communication scripts, conversation videos, training tools, and other tips - COVID-19 Response Resources <a href="https://www.capc.org/toolkits/covid-19-response-resources/">https://www.capc.org/toolkits/covid-19-response-resources/</a>

**Five Wishes:** A document that is legally valid in most states, the Five Wishes provides a format for choosing a surrogate decision maker and outlining end-of-life care preferences - <a href="https://fivewishes.org/">https://fivewishes.org/</a>

**Illinois Guardianship & Advocacy Commission:** Downloadable forms include Declaration for Mental Health Treatment, Illinois Statutory Short Form Power of Attorney for Health Care and Illinois Statutory Short Form Power of Attorney for Property - <a href="https://www2.illinois.gov/sites/qac/Forms/Pages/Forms.aspx#advancedirectives">https://www2.illinois.gov/sites/qac/Forms/Pages/Forms.aspx#advancedirectives</a>

**POLST Illinois:** POLST stands for Practitioner Orders for Life-Sustaining Treatment. The POLST form is a signed medical order that documents the types of treatments seriously ill people want at end-of-life - <a href="http://www.polstil.org/what-is-polst/">http://www.polstil.org/what-is-polst/</a>

# **Advocate Memory Center Program Happenings**

Advocate Memory Center's Clinical Social Worker / Program Coordinator, Danielle Dodson, MSW, LCSW, recently spoke with Open Arms Solutions regarding steps patients and their families can take following a new diagnosis of Alzheimer's disease or a related dementia. You can check out the conversation in the following video. Our team is available for community and provider education programs on a variety of topics. Contact us if you are interested in scheduling a program!



## **Advocate Memory Center Upcoming Events**



Walk To End Alzheimer's: As in years' past, the Advocate Memory Center is a proud participant in the Alzheimer's Association's Walk To End Alzheimer's. This year, for the health and safety of all participants, supporters are invited to walk individually or in small groups, rather than in one large inperson gathering. The Advocate Memory Center remains committed to supporting the valuable work of the Alzheimer's Association, and invites you to join our team by walking, donating, and/or fundraising.

Walk to End Alzheimer's

## **Advocate Memory Center Research Updates**

The Advocate Memory Center is involved in a number of clinical trials. The following studies are all open for screening.

**Art Therapy Research Study:** Study focused on examining the impact of art therapy on the relationship between patients and care partners

- Patients diagnosed with mild Alzheimer's disease
- Have a care partner who is willing to participate
- Study activities: 4 x 1.5 hour group art therapy sessions
- For more information call Danielle Dodson, (847) 720-6458

**Clarity AD:** Study focused on evaluating the safety and efficacy of the anti-amyloid antibody: BAN2401 (clinicaltrials.gov: NCT03887455)

- Patients with Early Alzheimer's Disease
  - Mild Cognitive Impairment or mild Alzheimer's Disease Dementia
- Study Drug: BAN2401 is an investigational treatment for the amyloid protein
- Ages: 50 90
- 18 months of infusions every 2 weeks
  - 50% chance of placebo for the 18 months
  - Opportunity to continue in the long term extension after 18 months where all participants receive the study treatment.
- For more information call Megon Holldorf, research coordinator, (224) 220-8133

**DIAN-TU:** Study focused on participants at risk for, or having genetic forms of, Alzheimer's disease. (clinicaltrials.gov: NCT01760005)

- Patients with known mutations in PSEN1, PSEN2, APP genes
- Families with multiple generations of Alzheimer's disease with symptoms starting before age 60
- Enrolling into a Cognitive Run-in period (testing of thinking abilities)
  - No drug treatment is currently available, but when a drug becomes available, and if qualified, participants would have the first opportunity to join one of the study drug treatments
- Ages: 18 80
- For more information call Megon Holldorf, research coordinator, (224) 220-8133

**U.S. POINTER:** Two-year study that will test whether changing to one of two different lifestyle programs can protect memory and thinking. (clinicaltrials.gov: NCT03688126)

- Ages: 60-79
- Have a family history (parent or sibling) with memory loss or dementia
- Are not regular exercisers (generally less than 3 times per week)
- For more information, call Evelyn Torres, research coordinator, at (847) 720-6457

Advocate Memory Center - Research

#### **Advocate Memory Center Support Programs**

All Advocate Memory Center support groups will continue to operate via Zoom due to the ongoing pandemic. If you already receive email reminders for support group meetings, you will receive updates regarding how to join the meetings by Zoom or phone. If you do not already receive updates, please contact Danielle Dodson, MSW, LCSW (847.720.6458 or <a href="mailto:dadson@aah.org">danielle.dodson@aah.org</a>) to request to be added to the email list for the group in which you are interested.

**Dementia Care Partner Support Group** – For family and friends caring for individuals diagnosed with Alzheimer's disease or a related dementia. 1st Friday of each month from 10:30 am - 12:00 pm

**Lewy Body Dementia Care Partner Support Group –** For family and friends caring for individuals diagnosed with Lewy Body Dementia (LBD). 3rd Wednesday of each month, 2:00 - 3:30 pm

**Younger Onset Dementia Care Partner Support Group** – For family and friends caring for individuals diagnosed with any form of dementia at or before age 65. 2nd Wednesday of each month, 5:30 – 7:00 pm

#### **COVID-19 Information**

As we did in the last newsletter, we want to remind you of the following reliable sources of information during the COVID-19 pandemic.

If you are concerned that you have been exposed to, or have symptoms of, COVID-19, you are advised to call the **Advocate Aurora Health COVID-19 Hotline** at **866.443.2584**.

**Advocate Aurora Health:** COVID-19 Resource Center; sections include a COVID-19 Symptom Checker, updates regarding Advocate Aurora policies, and links to relevant news articles - <a href="https://www.advocateaurorahealth.org/coronavirus-disease-2019">www.advocateaurorahealth.org/coronavirus-disease-2019</a>

**Alzheimer's Association:** Coronavirus (COVID-19) Tips for Dementia Caregivers; sections include tips for caregivers at home and tips for caregivers of those in residential care - <a href="https://www.alz.org/help-support/caregiving/coronavirus-(covid-19)-tips-for-dementia-care">https://www.alz.org/help-support/caregiving/coronavirus-(covid-19)-tips-for-dementia-care</a>

**Centers for Disease Control and Prevention (CDC):** Coronavirus (COVID-19); sections include "How to Protect Yourself" and "What to do if you are Sick" - www.cdc.gov/coronavirus/2019-nCoV

**Family Caregiver Alliance:** Coronavirus (COVID-19) Resources and Articles for Family Caregivers covers topics including in-home care, nursing home visitation guidelines, managing isolation, and caregiver self-care – <a href="https://www.caregiver.org/coronavirus-covid-19-resources-and-articles-family-caregivers">https://www.caregiver.org/coronavirus-covid-19-resources-and-articles-family-caregivers</a>

# **Additional Sources for Support, Information, and Referrals**

**Advocate Older Adult Services Information and Referral:** For information and guidance regarding both Advocate and non-Advocate resources and services for seniors. Leave a message and your call will be returned by a licensed social worker; 847.296.0737

<u>Alzheimer's Association Helpline</u>: Available 24 hours/day, 7 days/week for information about Alzheimer's disease and other dementias, referrals to local programs and services, and crisis support; 800.272.3900

<u>Illinois Department on Aging's Senior Helpline</u>: Information regarding state programs for older adults including Community Care Program (subsidized in-home care and other services for individuals with limited assets), home-delivered meals, and caregiver support; 800.252.8966

#### **Future Newsletters**

Thank you for taking the time to read this newsletter and stay connected with the <u>Advocate Memory Center</u>. Please feel free to let us know if there are topics you would like to see addressed in future editions. And, as always, please reach out if we can be of support to you, your family, your patients or clients.

Please send ideas, suggestions, links, etc. for future newsletters to Danielle Dodson, MSW, LCSW: <a href="mailto:danielle.dodson@aah.org">danielle.dodson@aah.org</a>.

#### **Donate to Support the Memory Center**

If you have found this newsletter, or other services of the Advocate Memory

Center, to be beneficial, we would be grateful to receive your support.

Donate



Advocate Aurora Safe Care Promise



Advocate Memory Center | Email Address | (847) 720-6464 | AMC Website

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