



Alzheimer's Resource of Alaska

Summer 2019
Volume 39
No. 1

NEWLY DEFINED ALZHEIMER'S-LIKE BRAIN DISORDER, GUIDELINES PROPOSED



A recently recognized brain disorder that mimics clinical features of Alzheimer's disease has for the first time been defined with recommended diagnostic criteria and other guidelines for advancing and catalyzing future research. Scientists from several National Institutes of Health-funded institutions, in collaboration with international peers, described the newly-named pathway to dementia, Limbic-predominant Age-related TDP-43 Encephalopathy, or LATE, in a report published in the journal *Brain*.

"While we've certainly been making advances in Alzheimer's disease research—such as new biomarker and genetic discoveries—we are still at times asking, 'When is Alzheimer's disease not Alzheimer's disease in older adults?'" said Richard J. Hodes, M.D., director of the National Institute on Aging (NIA), part of the NIH. "The guidance provided in this report, including the definition of LATE, is a crucial step toward increasing awareness and advancing research for both this disease and Alzheimer's as well."

Alzheimer's is the most common form of dementia, which is the loss of cognitive functions—thinking, remembering, and reasoning—and every-day behavioral abilities. In the past, Alzheimer's and dementia were often considered to be the same. Now there is rising appreciation that a variety of diseases and disease processes contribute to dementia. Each of these diseases appear differently when a brain sample is examined at autopsy. However, it has been increasingly clear that in advanced age, a large number of people had symptoms of dementia without the telltale signs in their brain at autopsy. Emerging research seems to indicate that the protein TDP-43—though not a stand-alone explanation—contributes to that phenomenon.

What is TDP-43?

TDP-43 (transactive response DNA binding protein of 43 kDa) is a protein that normally helps to regulate gene expression in the brain and other tissues. Prior studies found that unusually misfolded TDP-43 has a causative role in most cases of amyotrophic lateral sclerosis and frontotemporal lobar degeneration. However, these are relatively uncommon diseases.

A significant new development seen in recent research is that misfolded TDP-43 protein is very common in

older adults. Roughly 25 percent of individuals over 85 years of age have enough misfolded TDP-43 protein to affect their memory and/or thinking abilities.

"Recent research and clinical trials in Alzheimer's disease have taught us two things: First, not all of the people we thought had Alzheimer's have it; second, it is very important to understand the other contributors to dementia," said Nina Silverberg, Ph.D., director of the Alzheimer's Disease Centers Program at NIA. In the past many people who enrolled in clinical trials likely were not positive for amyloid.

"Noting the trend in research implicating TDP-43 as a possible Alzheimer's mimic, a group of experts convened a workshop to provide a starting point for further research that will advance our understanding of another contributor to late life brain changes," Silverberg explained. In addition to U.S. scientists, experts included researchers from Australia, Austria, Sweden, Japan, and the United Kingdom with expertise in clinical diagnosis, neuropathology, genetics, neuropsychology and brain imaging.

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Letter From The Executive Director

Dear Friends,

On June 30 Alzheimer's Resource of Alaska concluded its fiscal year, once again in the black. We're humbled by the generosity of all who have had a hand in that. Our thanks go out to each of you for your support. We're also immensely grateful for the efforts of our now former Development Director, Lorraine Guyer, whose hard work benefited ARA over the last eight years. Many of you know Lorraine and her great stewardship, so I'm certain you join me in extending our very best wishes to her as she begins her retirement.



As I review the past year I'm full of pride in this wonderful organization, for the work we performed throughout our state. We are, indeed, Alaskans serving Alaska, as we have since 1984. As an Executive Director, much of my time is spent planning for a future that ensures we will be able to meet the growing needs of Alaska's aging population and those who experience disabilities. We are all in this together, friends. I would like to hear from you about your vision of that future.

Some of our many efforts include:

- Our Education Department serving 1,284 individuals and 828 unique providers
- Care Coordinators serving 886 individuals
- Anchorage began offering the Memory Cafe (see page 4)

Caring for a person with Alzheimer's disease can have high physical, emotional, and financial costs. Developing good coping skills, a strong support network, and scheduling respite are keys that help caregivers reduce the stress of caring for a loved one with Alzheimer's disease. Staying physically active provides physical and emotional benefits. Meaningful engagement between care partners can also help. The informative article on page 7 offers suggestions for recreational activities that you can do with a loved one experiencing dementia. Activities that are suited to engage our loved ones living with disabilities can help maintain well-being for all involved.

Our programs continue to teach families, caregivers, and professionals about the various stages of dementia and about ways to deal with caregiving challenges. Support groups can be a critical lifeline. Some caregivers have found that joining a support group offers the opportunity to find respite, express concerns, share experiences, get tips, and receive emotional comfort. Visit page 11 to find a support group in your area or for more information on our telephone support group.

I thank you all for your support over the last fiscal year as we look forward to the next.

Sincerely,

Pamela Kelley
Executive Director

Newly defined Alzheimer's-like brain disorder, guidelines proposed

(from page 1)

LATE: A new research priority

The authors wrote that LATE is an under-recognized condition with a very large impact on public health. They emphasized that the “oldest-old” are at greatest risk and importantly, they believe that the public health impact of LATE is at least as large as Alzheimer’s in this group.

The clinical and neurocognitive features of LATE affect multiple areas of cognition, ultimately impairing activities of daily life. Additionally, based on existing research, the authors suggested that LATE progresses more gradually than Alzheimer’s. However, LATE combined with Alzheimer’s—which is common for these two highly prevalent brain diseases—appears to cause a more rapid decline than either would alone.

“It is important to note that the

disease itself is not new. LATE has been there all along, but we hope this report will enable more rapid advancement in research to help us better understand the causes and open new opportunities for treatment,” said Dr. Silverberg.

Laying groundwork for LATE

A key recommendation was for routine autopsy evaluation and classification of LATE. The researchers suggest the autopsy diagnosis be in three stages, according to where in the brain TDP-43 is detected:

- Stage 1: amygdala only
- Stage 2: amygdala and hippocampus
- Stage 3: amygdala, hippocampus and middle frontal gyrus

Additional recommendations include highlighting the great need for the development of biomarkers, further pathological studies, and the

generation of new animal models. Suggestions were provided for possible strategies to help guide future therapeutic interventions, including the importance of removing subjects with LATE from other clinical trials, which could significantly improve the chances of successful Alzheimer’s breakthroughs.

“It can’t be emphasized enough that this research wouldn’t have gotten this far—and can’t go further—without those who are willing to donate brain tissue after death,” said Dr. Hodes. “We are grateful for organ donors and their families, as well as all clinical trial participants, who truly are crucial to furthering discoveries that can lead to treatments and cures.”

National Institute on Aging: Reference: Nelson PT, et al. Limbic-predominant age-related TDP-43 encephalopathy (LATE): consensus working group report. *Brain*. 2019 Apr 30. DOI: 10.1093/brain/awz099

A warm invitation to our Neighborhood Memory Cafe!

The Memory Cafe offers an opportunity for persons living with dementia and their care partners to socialize and enjoy entertainment with peers.

Anchorage - Anchorage Senior Activity Center

1300 E 19th Avenue, Anchorage
Every 2nd Thursday, 1-2:30 pm
07/11, 08/08, 9/12

Wasilla - Wasilla Area Seniors, Inc. (WASI)

1301 S. Century Circle, Wasilla
Every 3rd Tuesday, 1-2:30 pm
07/16, 08/20, 09/17

[Click here to see our other events!](#)





Do memory problems always mean Alzheimer's Disease?

Many people worry about becoming forgetful. They think forgetfulness is the first sign of Alzheimer's disease. But not all people with memory problems have Alzheimer's.

Other causes for memory problems can include aging, medical conditions, emotional problems, mild cognitive impairment, or another type of dementia.

Age-Related Changes in Memory

Forgetfulness can be a normal part of aging. As people get older, changes occur in all parts of the body, including the brain. As a result, some people may notice that it takes longer to learn new things, they don't remember information as well as they did, or they lose things like their glasses. These usually are signs of mild forgetfulness, not serious memory problems, like Alzheimer's disease.

Memory Loss Related to Emotional Problems

Emotional problems, such as stress, anxiety, or depression, can make a person more forgetful and can be mistaken for dementia. For instance, someone who has recently retired or who is coping with the death of a spouse, relative, or friend may feel sad, lonely, worried, or bored. Trying to deal with these life changes leaves some people feeling confused or forgetful.

The confusion and forgetfulness caused by emotions usually are temporary and go away when the feelings fade. Emotional problems can be eased by supportive friends and family, but if these feelings last for more than 2 weeks, it is important to get help from a doctor or counselor. Treatment may include counseling, medication, or both. Being active and learning new skills can also help a person feel better and improve his or her memory.

Memory Loss Related to Medical Conditions

Certain medical conditions can cause serious memory problems. These problems should go away once a person gets treatment.

Medical conditions that may cause memory problems include:

- Tumors, blood clots, or infections in the brain
- Some thyroid, kidney, or liver disorders
- Drinking too much alcohol
- Head injury, such as a concussion from a fall or accident
- Medication side effects
- Not eating enough healthy foods, or too few vitamins and minerals in a person's body (like vitamin B12)

A doctor should treat serious medical conditions like these as soon as possible.

National Institute on Aging

Free Professional Webinars

Connect with us via Zoom; please register for link. To register for our professional webinars, please contact: Amber Smith - 907-586-6044 or email asmith@alzalaska.org.

Intellectual and Developmental Disabilities and Dementia

Tuesday, 7/30

Noon-1:00 pm

Intimacy and Dementia

Tuesday, 8/27

Noon-1:00 pm

Communication Tips for Caregivers

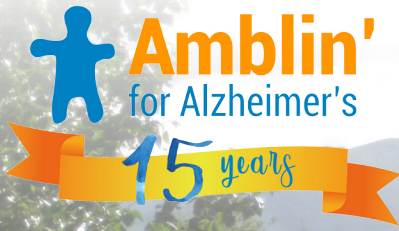
Tuesday, 9/17

Noon-1:00 pm

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Announcements...

STAY IN THE LOOP



This year's Amblin' for Alzheimer's was a huge success. Thanks to your participation and your generous donations, we raised:

\$56,568!



You help us achieve our mission of supporting Alaskans affected by Alzheimer's disease, related dementias, and other disabilities to ensure quality of life. We couldn't do it without you! Thanks for being part of Alzheimer's Resource of Alaska's story. Together, we are truly Alaskans serving Alaskans.



Pick.Click.Give.

Did you know?

You have until **August 31** to select Alzheimer's Resource of Alaska as a recipient of your Pick.Click.Give donation. Your Pick.Click.Give contributions can make a big difference, from helping us provide community support through support groups, Art Links, and education, to funding our Care Coordination program, which gives those needing support the opportunity to live in the home of their choice for as long as possible. All funds raised stay in Alaska and are often used as matching funds for grant proposals. [Click here to learn more!](#) (Note: The PFD website has an obligated warning when requesting access.)

Save The Date!

Put on your dancing shoes and save the date for the 35+ Singles Club event, "A Night to Remember."

Where: Carpenter's Hall, 407 Denali Street, Anchorage

When: September 14, Doors Open at 8:00 PM

\$18.00, tickets sold at door.

Must be 21 years of age or older to attend.

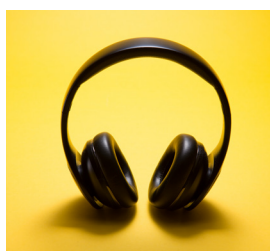




Recreational Activities: How to keep your loved ones active and engaged

Living with cognitive or physical frailty doesn't eliminate the need or desire to do activities as an adult, but it does change the ability to do those activities. The value of activity is an important one – it can nurture and encourage connection with others. It's more than just “keeping busy”; it is essential to a person's identity, autonomy, and belonging. Here are some examples of activities that can provide enrichment and a sense of belonging to your loved one:

- **Baking** – Your loved one can participate in a baking activity in many ways and with different levels of involvement. For example, they can decide what is to be baked or what recipe to use, they can measure or mix the ingredients, listen for the oven timer, be the test taster, or even input their own experiences and advice.



- **Listening to music** – Music is a powerful tool when considering activity. Music gives your loved one the opportunity to reminisce, but it also adds a physical element to the activity. For example, they may sing, dance, toe tap, clap, or drum along. It can also provide a time to relax or express current feelings.

- **Storytelling** – Giving your loved one the opportunity to tell stories about their life promotes values, self-esteem, and retains a sense of identity. You can do this by asking questions: “What makes you laugh?” “What's your idea of a real treat?” “What are you proud of?” You can also go through photo albums and scrapbooks to give them the chance to look back, reflect, and start conversations.



It's important to remember that if an activity doesn't work one day, to try it another day! It may be successful the next time. Think about the activities you can do with your loved one in a broad scope, and even some mundane tasks, such as cleaning or organizing, can be a chance to let your loved one engage and accomplish a sense of success.

To learn more about recreational activities, visit our website at www.AlzAlaska.org or call us at your nearest Alzheimer's Resource of Alaska location. We'd be happy to help you come up with ways to help you and your loved one enjoy the summer!

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1750 Abbott Road
907-561-3313

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565 University Avenue,
Ste. 2
907-452-2277

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3225 Hospital Drive
907-586-6044

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777 N. Crusey Street,
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ABC Presentations

What's a Memory Cafe?

Monday, 7/8
10-11:30 am or 5:30-7 pm

Driving & Dementia

Monday, 7/22
10-11:30 am or 5:30-7 pm

Sing a Song-Join the ARA Chorus

Monday, 8/5
10-11:30 am or 5:30-7 pm

What's the Deal with Brain Games?

Monday, 8/19
10-11:30 am or 5:30-7 pm

Project Lifesaver

Monday, 9/16
10-11:30 am or 5:30-7 pm

Grief and Grieving

Monday, 9/30
10-11:30 am or 5:30-7 pm

Savvy Caregiver*

Tuesdays, 7/16-8/20
5:30-7:30 pm
Registration is required.

Savvy Professional*

Monday, 8/12
8:30-4:30 pm
\$95.00 Registration fee
Registration is required.

Dementia Care Workshop*

Monday, 9/23
12:30-5 pm
\$45.00 Registration fee
Registration is required.

Brain Works*

Tuesdays, 8/20-10/8
10:30-11:30 am

Mind Matters Tuesdays*

Tuesdays, 8/20-10/8
1-2:30 pm

Mind Matters Wednesdays*

Wednesdays, 8/21-10/9
10-11:30 am

Mind Matters Thursdays*

Thursdays, 8/22-10/10
10-11:30 am

MAT SU VALLEY

777 N. Crusey Street,
Suite B101, 746-3413

ABC Presentations

The What, When, and How of Assisted Living

Monday, 7/15
1-2:30 pm

Driving & Dementia

Monday, 7/29
1-2:30 pm

20 Questions, 100 Answers, 6 Perspectives (Part I)

Monday, 8/12
1-2:30 pm

20 Questions, 100 Answers, 6 Perspectives (Part II)

Monday, 8/26
1-2:30 pm

Wandering & Dementia: "I Just Want to Talk"

Monday, 9/9
1-2:30 pm or 5:30-7 pm

Backing Out of Time, Movie & Discussion

Monday, 9/23
1-2:30 pm or 5:30-7 pm

Dementia Care Workshop*

Wednesday, 9/17
1-5:30 pm,
\$45.00 Registration fee
Registration is required.

Mind Matters*

Wednesdays, 8/7-9/25
10:30-Noon
Registration is required.

Brain Works*

Wednesdays, 8/7-9/25
1:30-3 pm
Registration is required.

* Registration Required

Art Links

Anchorage
1750 Abbott Road
Every Friday, 11-Noon

JUNEAU

3225 Hospital Drive,
586-6044

ABC Presentations

The Power of Music

Tuesday, 7/23
12-1:30 pm or 5:30-7 pm

The What, When, and How of Assisted Living

Thursday, 8/29
12-1:30 pm or 5:30-7 pm

PAC-"Normal" Aging vs "Not Normal" Aging

Wednesday, 6/19
12-1:30 pm or 5:30-7 pm

Memory Screenings*

Wednesday, 9/11
10 am-4:00 pm
Registration is required.

See pages 4 & 5 for information about current Memory Cafe and Professional Webinar offerings.

FAIRBANKS

565 University Ave., #2,
452-2277

ABC Presentations

When Does Forgetting Become a Disease?

Tuesday, 7/16
5:30-7 pm

Recreational Activities

Tuesday, 8/20
5:30-7 pm

End of Life

Tuesday, 9/17
5:30-7 pm

Savvy Caregiver*

Wednesdays, 7/24-8/28
5:30-7:30 pm
Registration is required.

Virtual Dementia Tour*

Monday, 8/26
10-5 pm
Registration is required.

Mind Matters*

Thursdays, 8/15-10/3
1-2:30 pm

Statewide Webinars *Registration is required.*
Connect with us via Zoom; please register for link.

Family Caregiver Webinars

Gay Wellman: 822-5620, gwellman@alaska.org

Dining & Dementia

Wednesday, 7/10 10:30-Noon	Saturday, 7/13 1-2:30 pm
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Introduction to the Dementias

Wednesday, 8/7 10:30-Noon	Saturday, 8/10 1-2:30 pm
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Behaviors that Challenge

Wednesday, 9/11 10:30-Noon	Saturday, 9/14 1-2:30 pm
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Savvy Caregiver

Saturdays, 8/24-9/28
10-Noon

(Please refer to page 5 for our Professional Webinars.)



Caregiver Support Groups around the state

A safe place for caregivers, family and friends of persons with dementia to share experiences and solutions.

Location	Date & Time	Contact
Statewide Telephone Support Group	Every 1st Saturday, 1-2 pm Every 3rd Wednesday, 1-2 pm	Dial in using 1-877-216-1555, Code #927989. For additional information, contact Gay Wellman, 822-5620 or 800-478-1080x5
Anchorage		
Alzheimer's Resource of Alaska, 1750 Abbott Road	Every 4th Thursday, 5:30-7 pm	Debbie Chulick, 561-3313
Eagle River		
Holy Spirit Episcopal Church, 17545 N. Eagle River Loop Road	Every 2nd Thursday, 5-6:30 pm	Debbie Chulick, 561-3313
Fairbanks		
Alzheimer's Resource of Alaska, 565 University Ave. Ste. 2	Every 2nd Tuesday, 5:30-7 pm Every 3rd Tuesday, 11:30-1 pm	Joan Adams, 452-2277
Homer		
Homer Senior Center	Every 2nd & Every 4th Thursday, 2:30-3:30 pm	Pam Hooker, 235-7655
Ketchikan		
Ketchikan Senior Center, Upper Level	Call for current schedule.	Bernice, 255-8080
Kodiak		
Kodiak Senior Center, 302 Erskine Avenue	Every 4th Thursday, 12:30-1:30 pm	486-6181
Mat-Su Valley		
Alzheimer's Resource of Alaska, 777 N. Crusey St., Ste. B101	Every 2nd Tuesday, 1:30-3 pm	Janice Downing, 746-3413
Palmer Senior Center, 1132 S. Chugach Street	Every 1st Friday, 10-11:30 am	Kim Jung, 746-3413
Primrose Retirement Community, 889 Elkhorn Drive	Every 3rd Thursday, 10-11:30 am	Janice Downing, 746-3413
Seward		
Seward Senior Center	Every 4th Thursday, 1-2 pm	244-5604
Sitka		
Brave Heart Volunteers 120 Katlian Street	Call for current schedule.	747-4600
Soldotna		
Soldotna Senior Center	Every 2nd and Last Tuesday, 1-3 pm	Judy Warren, 262-1280
Sterling Senior Center	Every 1st Tuesday, 1-2 pm	Judy Warren, 262-1280
Talkeetna		
Sunshine Community Health Center 34300 Talkeetna Spur Rd.	Every 1st Monday	Janice Downing, 746-3413

Not seeing a support group that's right for you? Give our Education Department a call at 907-561-3313. We'll be happy to help you find the right solution for you.



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Up to \$2,500 per year is available to an individual with Alzheimer's disease or related dementia (ADRD) to purchase items or services. Some restrictions apply.

Email applications or questions to: ksilver@alzalaska.org.

**Visit: AlzAlaska.org
or call 1-800-478-1080**

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