# Alzheimer's Resource of Alaska

August 2022 Volume 48 alzalaska.org

Living with Dementia and the Rhythm of Life

The Stigma of Dementia and Its Impact on Caregivers - Part I

New Caregiver Resource Guide

Find more helpful stories and perspectives on our website blog @ alzalaska.org/blog

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#### Offices & Contact Information

#### **Anchorage**

1750 Abbott Rd. Education (907) 561-3313 CCRA\* (907) 677-6789

#### **Fairbanks**

565 University Ave., Ste. 2 Education (907) 452-2277

#### Mat-Su Valley

777 N. Crusey St., B101, Wasilla, AK Education (907) 746-3413 CCRA\* (907) 746-3445

#### Juneau

2354 Mendenhall Loop Rd. Education (907) 586-6044 CCRA\* (907) 500-7456

#### **Copper River Basin** (907) 822-5620

#### Statewide

Toll Free within Alaska outside of Anchorage (800) 478-1080

\* Care Coordination Resource of Alaska

#### **Board of Directors**

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#### **Upcoming Events**

MAYOR'S CHARITY BALL

#### JOIN US OCTOBER 8, 2022

At The Dena'ina Civic Convention Center

Tickets can be purchased through mayorscharity.org.

\* Auction proceeds benefit Alzheimer's Resource of Alaska \*





Funds raised stay in Alaska, supporting those affected by Alzheimer's, related dementias, and other disabilities.

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#### **Letter** from the **Executive Director**

Dear Friends,

We are enjoying this beautiful summer full of gratitude, having launched it with the season of long days and bright skies with one of our most successful Amblin' for Alaska events ever. More than two hundred neighbors, friends and supporters joined us at the Anchorage Golf Course for breakfast sponsored by Sal's Catering before our walk along the cart paths of the back nine. The pure joy of assembling in person, after two years of Virtual Amblin,' set the mood. Together we raised more than \$90,000 to help us continue our important work.



Over the last year, Alzheimer's Resource of Alaska has taken a leading role in the <u>Alaska Dementia Action Collaborative</u>. One of the first tangible products of the Collaborative, with funding from the Alaska Mental Health Trust and AARP-Alaska, is a 41-page Caregiver Resource Guide. You'll see a copy of the <u>cover on p.5</u>, and for those of you reading online it's a live link to the Guide. This comprehensive guide offers simple to use guidance for family caregivers no matter what stage they may be at on the journey. Caregivers might be "Worried and Wondering", or "Definitely Concerned". They might be noticing "Obvious Changes – Now What?", or recognizing "I Need More Help", or acknowledging "Acceptance and Support". Each of these stages, and more, are explored in respectful and helpful ways.

ARA's active participation in groups like The Alaska Dementia Action Collaborative, where I chair the steering committee, or AGEnet, where I serve on the Board of Directors, are beneficial to those we serve. A coordinated advocacy effort this year with AARP-AK, AGEnet (the statewide network of senior service providers) and the Alaska Commission on Aging to encourage creating an Alzheimer's and dementia awareness program within the Department of Health's Division of Public Health. This successful effort will position the state's Division of Public Health to participate in federal funding to increase dementia and brain health awareness.

Finally, please join me in welcoming Kara Thrasher-Livingston, Sheryl Cook and Larry Duffy to the ARA Board of Directors! We know their commitment and enthusiasm will help advance our mission in the years ahead.

Sincerely,

Pamela Kelley Executive Director

Make a Donatetion

#### Living with Dementia and the Rhythm of Life

The power of rhythms can be harnessed to help us through many illnesses, including dementia and other neurological disorders and can help relieve the stresses of daily living.

#### By: Ann Farris

The human relationship to sound and rhythm starts early. In fact, even before you were born, you began to develop an auditory system. Already, you were in a world of sound: of breath and heartbeat, of rhythm and vibration. When you heard a lullaby as a toddler, it offered comfort and a feeling of happiness. As a young adult, songs that provided a beat and rhythm offered you meaning and enjoyment. As an older adult these are the special songs stored in your brain and bring back fond memories.

There is a strong connection between music and the mind. This powerful connection explains why a man in the later stages of dementia, barely able to communicate, will liven up when listening to his favorite music. Closely related to music is rhythm, "a strong, regular, repeated pattern of movement or sound". In fact, rhythm is as elemental to breathing and other bodily functioning as it is to singing and dancing. Our lives are driven by rhythm.

In her Master's Thesis, "Music Therapy and Percussion for People with Dementia", Jaclyn Bell focuses on the potential of percussion and

other rhythm-based music therapies. She writes, "People with dementia may gradually lose the ability to sing as the disease progresses and the use of percussion may allow for continued musical participation... Studies have

shown that rhythm interventions can sometimes elicit more of a response than singing."

There are a variety of ways to utilize rhythm to enhance the quality of life for someone living with dementia: start a drum circle with friends, keep the beat while listening to music, dance, exercise. Creating homemade instruments is always fun: fill an empty medicine bottle with rice and you have a maraca; books, pots, and tables make great drums. Finally, utilize rhythm to assist in the desired outcome of an activity: soft music before bed; relaxing music while bathing, upbeat music while folding laundry or cleaning.

There are ways to incorporate music into activities for everyone. The key to assisting those living with dementia is



selecting music that meets the need. For those in later stages of dementia, a more measured approach can be helpful. In her article, "How to use music to help a loved with dementia", Jan Maier suggests starting slow and tailoring the activity to the response of the person living with dementia: "Keep sessions short, perhaps up to a half hour. Tailor the length of the sessions to how much your loved one enjoys them."

A powerful visual of how rhythm can assist those with dementia or other neurological disorders is the video of a man living with Parkinson's disease. During physiotherapy sessions, the man's gait is enhanced first by the therapist counting "1. 2, 1, 2...", and secondly by

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listening to a favorite song. These rhythmic cues assist the brain in going through the motions of walking.

The beat of our hearts, the rise and fall of our breathing, the movement of our bodies through each day demonstrate the natural rhythms of life. The power of rhythms can be harnessed to help us through many illnesses, including dementia and other

neurological disorders and can help relieve the stresses of daily living. In his book Musicophilia, renowned neuroscientist Oliver Sacks writes that rhythm is one of the most basic and fundamental parts of the human experience and remains with us until the very end. We agree, and to quote from the musical Sweet Charity, "The rhythm of life is a powerful beat!"

### The Stigma of Dementia and Its Impact on Caregivers – Part I

December 17, 2019 — Rhonda Feldman, Ph.D., C.Psych Reitman Centre Team, <u>dementiacarers.ca</u>

#### What is the stigma of dementia?

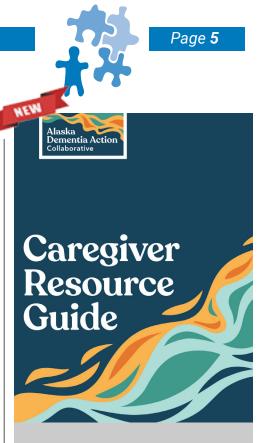
In a general sense, stigma is something that sets a person apart from others, something that takes away from one's character or reputation. Stigma carries with it disgrace and humiliation. Stigma around dementia refers to the concept that dementia diminishes someone or makes them worth less than others. Stigma implies that cognitive functioning defines a person's value. Even the word "demented" is an insult in common use. Some cultures see dementia as contagious. When someone has dementia, the disease becomes the family's shame, and they keep it hidden.

#### Small changes can make a real difference

We all have our own biases and vulnerabilities. Research has shown that stigma is best challenged through understanding and interaction. Instead of trying to end stigma, it is much more helpful to talk about realistic small changes. We want to connect with the person with dementia as an individual, rather than their symptoms.

Stigma is one of the factors that leads to caregiver isolation. For example, for the past few years a client of mine has been caring for his wife who has Alzheimer's dementia. Several years ago, a friend told him

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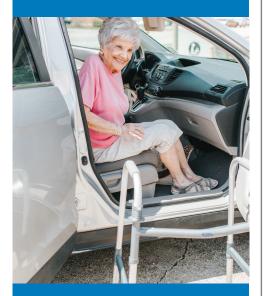


We're excited to have a new resource to offer care partners – family members, friends, and neighbors – who care for someone with Alzheimer's disease and related dementias.

The new Alaska Caregiver Resource Guide was published by the Dementia Action Collaborative, a coalition of public-private partners committed to preparing Alaska State for the growth of the dementia population.

Find out more and download the guide at <a href="https://www.alzalaska.org/caregiver-resource-guide/">https://www.alzalaska.org/caregiver-resource-guide/</a>

#### **Grants Available**



Funding is available for services and and to support the needs of people with Alzheimer's disease or related dementias (ADRD).

The Alaska Mental Health
Trust Authority provides grants
up to \$2,500 per fiscal year;
available for individuals living
with Alzheimer's disease or
related dementia (ADRD) to
purchase items or services that
are not covered by other funding
sources to help improve quality
of life and increase independent
functioning.

Details at: http://www.alzalaska.org/mini-grant

For more information contact: Kevin Silver at 907-561-3313 or email <u>ksilver@alzalaska.org</u>

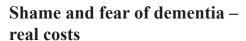


Learn More →

#### The Stigma of Dementia and Its Impact on Caregivers – Part I

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that she would not visit because she "didn't like sick people." A few years have passed since that conversation, and my client continues to carry feelings of rejection and shame. Even if his friend did not mean to hurt him, her comment sent the message that someone who is sick with dementia isn't worth spending time with, and my client experienced stigma by association.



We are talking about a complex issue with serious emotional and practical implications. Stigma impacts how people with dementia think about themselves, and what they expect from others in their lives. Sometimes people avoid seeing their doctor because of the stigma associated with a diagnosis of cognitive impairment. After a diagnosis of dementia people often feel ashamed of the label. because they expect others to treat them as though they have a shameful illness. Because dementia affects a person's ability to communicate and engage with people, they might



worry that they seem "stupid" or "incapable." I have a client whose husband did not tell his partners at his business firm that he was getting confused. He made a crucial and costly mistake and he was forced to retire. Informing his business partners about changes to health that would impact the business was in the partnership agreement. Ironically, if he had felt safe to share his diagnosis, he could have left the business with his reputation intact.

In reality, people with mild and moderate dementia can continue to live full and productive lives if they make appropriate modifications. Unfortunately, people with dementia are often defined by their symptoms. Dementia symptoms are not necessarily expressed the same way in all people, and symptoms change

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#### The Stigma of Dementia and Its Impact on Caregivers – Part I

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over time in a person with dementia. Variability adds to misunderstandings about dementia. I hear all the time how frustrating it can be when someone's family member with dementia cannot remember the answer to a question from 5 minutes ago but can remember the details of a vacation they took as a child. Sometimes people question whether their family member really has dementia because they are able to remember the past. In fact, this difference in recall happens because of differences in the way the brain stores memories. With dementia, the brain has difficulty storing new information. Accessing memories about the past is easier because the connections between brain cells are stronger.

Assumptions are a form of stigma. When someone with dementia has a lapse of attention during a conversation, people might assume that they are unable to remember anything or understand complex ideas. They might be left out of other discussions, even about things that are important to them. I often hear from my clients how frustrating it is that people talk to them and ignore their family member with dementia.

#### Stigma by association – impacts caregivers too

I mentioned a caregiver whose friend wouldn't come to visit him and his wife. Not only was it a rejection of the woman with dementia, it was also a rejection of her husband. This is stigma by association. Caregivers of people with dementia are also affected by stigma. It is easy enough to see how stigma leads to isolation, which is a strong contributor to caregiver burden.

Who to tell about the diagnosis is a dilemma for caregivers, because revealing the diagnosis can increase stigma. My clients tell me that they feel conflicted about sharing this information with friends or family. On the one hand, they crave the emotional and practical support that comes from having other people aware of the challenges. On the other hand, caregivers want to preserve their family member's dignity and privacy. I worked with one woman who had many compassionate people in her life who knew nothing about how much she was suffering. She was so good at hiding the extent of her husband's impairments that no one realized that he needed any help from her.

It is hard for caregivers to avoid the trap of all-or-nothing thinking when it comes to revealing the diagnosis, while actually telling a few valued people may be enough for a sense of connection. That phrase "at times like these you really learn who your friends are" holds true for dementia. People tell me that it is surprising who lets them down, and also how support sometimes comes from surprising places.

In <u>Part II</u> of this article (find it on our <u>website blog @ alzalaska.org</u>), we will continue to explore how we can make small changes to counter stigma to be helpful to people with dementia and their families.

For more information and assistance on caregiving challenges in managing dementia, please call us at 907-561-3313 or visit our website, alzalaska.org.

#### Pick.Click.Give.

Alaskans may choose to add or adjust their pledges online through **August 31**, please consider making a gift to **Alzheimer's Resource of Alaska**.

visit: pfd.alaska.gov

#### **Donations Made In Honor or Memory of**

between January 1 - July 1, 2022 — alphabetized by honoree



Celia Koelsch

Amelia

Harry Prichard

Gil

Catherine Coon

Karen

Heather Jacox

Sharon

Sherri Roberds

Teresa's Mom

Keri Clark

Elva Amidon

Ronald & Sandra Amidon

Ann and Ray Rodgers

**Chottie Angst** 

Susan Rymzo

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Roger Birckhead

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**Shirley Braspenninckx** 

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Leslie Willocks

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Cesar Carmona



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**Gladys Coster** 

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Jan and Larry Dinneen

Laurie Evans-Dinneen

Len Ferucci

Patricia Ferucci

PRH

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Mari Gibson

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Sandra & Edward Sanders

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Marjorie & Robert Paulson

Charles Helmick, Jr.

Jeff Helmick

Leiza Johnson

**Debbie Hestes** 

William Hestes

**Dorothy Hugg** 

Wayne Holmes &

Jonell Snook-Holmes

Jan Janzen

Rebecca Marinelli

Anita Kirk

Joanie Kirk

Sandy Knight

Tyler Woznica

Preferred Care

**Charlene Konestago** 

Pioneers of AK Women's

Igloo #11

Victor LaForge

Cheryl Snyder

Lynne Larson

Judy Simonds

**Dorothy Magette** 

John and Jackie Brunton \*

Rev. Russell H. McConnell, Beatrice McConnell,

& Robert McConnell

Ruth McConnell Benson

**Rusty Moore** 

Michael Dunn

M. L. Morgan

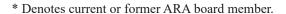
Michele L. Berns

**Kim Peterson** 

Teresa Richards

**Cheryl Ponder SWONAP** 

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#### **Donations Made In Honor or Memory of, cont.**

between January 1 - July 1, 2022 — alphabetized by honoree



Moveta Posma Trust

**Charles Powers** 

Joan Cullinane

**Irvine Pyett** 

**Dennis Stock** 



Carey Mills

**Audrey Roberts** 

Susan June

Donna Piszczak

Pamela Kelley

Marta Zamiska

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Aunt Bev & Bobbie Scribner

Chris Wilson

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Steve Adams

Jim & Phyllis Serfling

Krista Shelby

**Bette Shaver** 

Kathryn Stoltzfus

Paula Skyarch

Jacque Good



Linda Shepard

Werner Stutzer

Elena Hartford

**Katy Sutherland** 

Abby McLane

**Craig Thompson** 

Brad and Mary Reeve

Alaskan Brewing Co.

**Phyllis Thompson** 

Kristin George \*

Patricia Versnick

Rhonda S. Scott

Larry W.

Aunt Shelly Cassano

**Evelyn White** 

Louise Smith

Regina Wilgus

Oma

Jim Wilgus

Gene Williamson & Marlene Ronnie Williamson

Carrie Berrey

Tom Williamson & Ann Farris

Joanne Younie

Robert & Melissa Burke



Bruce Pozzi

Shawn Abel

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Stephen Peacock

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Carrie Schnell

Maribeth & Griff Steiner

Truman & Roberta Struck

Dolores Tamagni

Daniel Dieckgraeff &

Denise Thanepohn



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#### Caregiver Support Groups throughout Alaska

Groups are free to join. ARA logo # indicates an ARA facilitator. Contact facilitator in advance for zoom link or call-in phone number.



Support groups provide a way for people with a common experience to help and learn from each other. They can be an important source of social and emotional support, as well as a great way to see what works for others and learn about local services.

Most groups are currently available statewide over the phone or via Zoom. For this reason most people find it helpful to identify groups with days and times that work best with your schedule regardless of location.



You might also be interested in joining our Facebook Caregiver Support Group. This is a closed group and you will need to request

#### **MIND MATTERS**

is an education and support program for individuals with early memory loss.



This program goes beyond the confines of a traditional support group and offers participants a chance to share experiences while engaging in a variety of meaningful activities including volunteering, gardening, writing and listening to guest speakers.

For more info contact: Debbie Chulick at 907-561-3313 or dchulick@alzalaska.org

of 20011 link of our in phone number.				
Statewide Telephone Support Group	٠	Every 1st Saturday, 1–2:00 pm For additional info, contact † Gay Wellman, 822-5620 or 800-478-1080		
Dial in using:  Code 927989#  No registration required	و	Every 3rd Wednesday, 1–2:00 pm For additional info, contact † Debbie Chulick, 561-3313 or 800-478-1080		
Statewide Care Partner Support	<u>.</u>	Every 2nd & 4th Tuesday, 1-2:30 pm Every 2nd & 4th Saturday 10:30am-12 pm CONTACT: Gay Wellman, gwellman@ alzalaska.org 822-5620 or 800-478-1080		
Grieving Caregiver Support	<u>.</u>	Every 1st & 3rd Thursday, 1-2:30 pm CONTACT: †Gay Wellman, gwellman@ alzalaska.org 822-5620 or 800-478-1080		
Anchorage	J	Every 4th Thursday, 5:30-7 pm CONTACT: † Debbie Chulick, 561-3313		
Eagle River	<u>.</u>	Every 2nd Thursday, 5:30-7 pm CONTACT: Debbie Chulick, 561-3313		
Fairbanks	<u>.</u>	Every 2nd Tuesday, 4:30-6 pm Every 3rd Tuesday, 1:00-2:30 pm CONTACT: Joan Adams, 452-2277		
Homer		Call for current schedule CONTACT: Pam Hooker, 235-7655		
Juneau / Southeast AK		Call for current schedule CONTACT: Aimee 463-6177		
Ketchikan		Call for current schedule. CONTACT: Bernice, 255-8080		
Kodiak		<b>Every 4th Thursday, 12:30–1:30</b> pm CONTACT: <u>486-6181</u>		
Mat-Su Valley	J	Every 2nd Tuesday, 1:30–3 pm CONTACT: † Janice Downing 746-3413		
Seward		Every 4th Thursday, 1–2 pm CONTACT: 244-5604		
Sitka		Call for current schedule CONTACT: 747-4600		
Soldotna		Every 2nd and Last Tuesday, 1–3 pm Every 1st Tuesday, 1–2 pm CONTACT: Dani Kebschull, <u>262-1280</u>		
Sutton, Palmer, Chickaloon, Glacier View	<u>.</u>	Every 1st Friday, 10–11:30 am CONTACT: TKim Jung, 746-3413		
Talkeetna, Willow, Trapper Creek	<u> </u>	Every 1st Monday, 10–11:30 am CONTACT: TKim Jung, 746-3413		



#### Classes & Events around the State

Classes and events are available statewide, online via Zoom. All classes listed below require registration.

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#### **CAREGIVING 101**

**Making Visits Positive** Thurs, 7/7, 12pm-1:30pm

Juneau — In-Person

Fri, 7/8, 1pm-2:30pm

Webinar REGISTER

**Nutrition and Brain Health:** What we need to know Wed, 7/13, 11am-12:30pm Webinar REGISTER

Alive Inside, movie showing Wed, 7/20, 5:30pm-7pm Fairbanks — In-Person

**Frontotemporal Dementia** Tue, 7/26, 1pm-2:30pm

Webinar REGISTER

Thurs, 7/28, 1pm-2:30pm Mat-Su — In-Person

When Does Forgetting Become a Worry? Fri, 7/29, 12pm-1:00pm

Webinar REGISTER

**Being the Decision Maker** Thurs, 8/4, 12pm-1:30pm

Juneau — In-Person

Fri, 8/5, 1pm-2:30pm Webinar REGISTER For more information or registration assistance contact: 907-561-3313 from Anchorage, or 1-800-478-1080

Family Meeting Wed, 8/10, 11am-12:30pm Webinar REGISTER

**Downsizing** and Decluttering Fri, 8/19, 1pm-2:30pm Webinar REGISTER

**Common Challenges Faced by Dementia Care Partners** Mon, 8/22, 1pm-2:30pm

Webinar REGISTER -0R-

Tue, 8/23, 1pm-2:30pm Mat-Su — In-Person

**End of Life** Thurs, 9/8, 12pm-1:30pm Juneau — In-Person

Fri, 9/9, 1pm-2:30pm

Webinar REGISTER

**Engaging People Living with Dementia** Tue, 9/13, 3pm-4:30pm Webinar REGISTER

 $-\Omega R-$ Fri, 9/16, 3pm-4:30pm Anchorage — In-Person

Clues & conversations: Understanding Alzheimer's Disease Wed, 9/14, 1pm-2:30pm Webinar REGISTER

**Honoring Connection: Improve Communication** Mon, 9/19, 1pm-2:30pm

Webinar REGISTER

Tue, 9/20, 1pm-2:30pm Mat-Su — In-Person

Creating Moments of Joy Wed, 9/21, CANCELLED

Fairbanks In-Person

#### **ESAVVY CAREGIVER**

Learn caregiver skills and knowledge to provide the highest level of care for loved ones and yourself.

#### REGISTER HERE

For more information or registration assistance: Gay Wellman at 907-822-5620 or email: gwellman@alzalaska.org

> Saturday, 7/9-8/13 1:30 pm - 2:30 pm

**Art Links** 1-1:45pm To register contact: Janice Downing at 🅵 746-3413 or email: idowning@alzalaska.org

Thursday, 4/7 & 4/21 Thursday, 5/5 & 5/19 Thursday, 6/2 & 6/16

Online meeting

Friday, 7/8 & 7/22 Friday, 8/12 & 8/16 Friday, 9/9 & 9/23 Mat-Su — In-Person

Memory Café To register contact Ann Farris at 561-3313 or email: afarris@alzalaska.org

Thursday, 7/14, 1pm Thursday, 8/11, 1pm Thursday, 9/8, 1pm

Online meeting



Chorus program to support people with dementia and their care-partners To register contact: Ann Farris at 907-561-3313 or email: afarris@alzalaska.org

#### **Professional Webinars**

Contact: Amber Smith: 586-6044 or asmith@alzalaska.org

**Activity Box Ideas for** People Living with Dementia
Tuesday, 7/19, 12 pm - 1:00pm
Webinar REGISTER HERE

**Music in Dementia Care** Tuesday, 8/23, 12 pm - 1:00pm Webinar REGISTER HERE

**Activities are Everywhere** Tuesday, 6/21, 12 pm - 1:00pm Webinar REGISTER HERE



#### **™** Mind Aerobics

Online meetings

12-week course meeting twice per week

For Alaskans worried about Memory Loss who want to keep their mind fit and engaged.

**Contact: Ken Helander** 

907-561-3313 or khelander@alzalaska.org

Mind Sharpener™ Tue & Thur, 7/12-9/29, 10am-11am

Mind Works™

Mon & Wed. 8/3-11/2, 1pm-2 pm



## Thanks for Amblin'! Alzheimer's Resource of Alaska



We were overwhelmed with gratitude at the turnout for our return to an in-person Spring event, Amblin' for Alzheimer's.

Thank you to our Beacon sponsor, **ConocoPhillips**, and all our supporters and **volunteers** that contributed to a successful event, helping us further achieve our on-going mission to support Alaskans affected by Alzheimer's disease, related dementias and other disabilities to ensure quality of life.























