Living with Dementia and the Rhythm of Life  p.4

The Stigma of Dementia and Its Impact on Caregivers – Part I  p.5

New Caregiver Resource Guide  p.5

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

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

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

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

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

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

* Care Coordination Resource of Alaska

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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*

**THE ANCHORAGE SOCIAL CLUB PRESENTS:**
"A Night to Remember"
September 17, 2022
Dance the night away for 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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*www.alzalaska.org*  *www.ccralaska.org*

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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 *Alaska Dementia Action Collaborative*. 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 cover on p.5, 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
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 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 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.”

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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!”

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 https://
www.alzalaska.org/caregiver-
resource-guide/

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

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

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

(Cont. on next page)
The Stigma of Dementia and Its Impact on Caregivers – Part I

(Cont. from previous page)

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.

Shame and fear of dementia – real costs

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

(Cont. from previous page)

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 Part II of this article (find it on our website blog @ alzalaska.org), 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.

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
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* Denotes current or former ARA board member.

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(Cont. on next page)
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* Denotes current or former ARA board member. Other donors are noted in our Annual Report.
### 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 to join.

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### 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

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<table>
<thead>
<tr>
<th>Caregiver Support Groups</th>
<th>Details</th>
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<tbody>
<tr>
<td><strong>Statewide Telephone Support Group</strong></td>
<td>Every 1st Saturday, 1–2:00 pm&lt;br&gt;Dial in using: Code 927989# No registration required&lt;br&gt;For additional info, contact Gay Wellman, 822-5620 or 800-478-1080</td>
</tr>
<tr>
<td><strong>Statewide Care Partner Support</strong></td>
<td>Every 2nd &amp; 4th Tuesday, 1-2:30 pm&lt;br&gt;Every 2nd &amp; 4th Saturday 10:30am-12 pm&lt;br&gt;CONTACT: Gay Wellman, <a href="mailto:gwellman@alzalaska.org">gwellman@alzalaska.org</a> 822-5620 or 800-478-1080</td>
</tr>
<tr>
<td><strong>Grieving Caregiver Support</strong></td>
<td>Every 1st &amp; 3rd Thursday, 1-2:30 pm&lt;br&gt;CONTACT: Gay Wellman, <a href="mailto:gwellman@alzalaska.org">gwellman@alzalaska.org</a> 822-5620 or 800-478-1080</td>
</tr>
<tr>
<td><strong>Anchorage</strong></td>
<td>Every 4th Thursday, 5:30–7 pm&lt;br&gt;CONTACT: Debbie Chulick, 561-3313</td>
</tr>
<tr>
<td><strong>Eagle River</strong></td>
<td>Every 2nd Thursday, 5:30–7 pm&lt;br&gt;CONTACT: Debbie Chulick, 561-3313</td>
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<tr>
<td><strong>Fairbanks</strong></td>
<td>Every 2nd Tuesday, 4:30–6 pm&lt;br&gt;Every 3rd Tuesday, 1:00–2:30 pm&lt;br&gt;CONTACT: Joan Adams, 452-2277</td>
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<tr>
<td><strong>Homer</strong></td>
<td>Call for current schedule&lt;br&gt;CONTACT: Pam Hooker, 235-7655</td>
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<tr>
<td><strong>Juneau / Southeast AK</strong></td>
<td>Call for current schedule&lt;br&gt;CONTACT: Aimee 463-6177</td>
</tr>
<tr>
<td><strong>Ketchikan</strong></td>
<td>Call for current schedule.&lt;br&gt;CONTACT: Bernice, 255-8080</td>
</tr>
<tr>
<td><strong>Kodiak</strong></td>
<td>Every 4th Thursday, 12:30–1:30 pm&lt;br&gt;CONTACT: 486-6181</td>
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<tr>
<td><strong>Mat-Su Valley</strong></td>
<td>Every 2nd Tuesday, 1:30–3 pm&lt;br&gt;CONTACT: Janice Downing 746-3413</td>
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<tr>
<td><strong>Seward</strong></td>
<td>Every 4th Thursday, 1–2 pm&lt;br&gt;CONTACT: 244-5604</td>
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<tr>
<td><strong>Sitka</strong></td>
<td>Call for current schedule&lt;br&gt;CONTACT: 747-4600</td>
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<tr>
<td><strong>Soldotna</strong></td>
<td>Every 2nd and Last Tuesday, 1–3 pm&lt;br&gt;Every 1st Tuesday, 1–2 pm&lt;br&gt;CONTACT: Dani Kebschull, 262-1280</td>
</tr>
<tr>
<td><strong>Sutton, Palmer, Chickaloon, Glacier View</strong></td>
<td>Every 1st Friday, 10–11:30 am&lt;br&gt;CONTACT: Kim Jung, 746-3413</td>
</tr>
<tr>
<td><strong>Talkeetna, Willow, Trapper Creek</strong></td>
<td>Every 1st Monday, 10–11:30 am&lt;br&gt;CONTACT: Kim Jung, 746-3413</td>
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Classes & Events around the State
Classes and events are available statewide, online via Zoom. All classes listed below require registration.

CAREGIVING 101
For more information or registration assistance contact: 907-561-3313 from Anchorage, or 1-800-478-1080

Making Visits Positive
Thurs, 7/7, 12pm-1:30pm
Juneau — In-Person
—OR—
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
—OR—
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
—OR—
Fri, 8/5, 1pm-2:30pm
Webinar | REGISTER

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

End of Life
Thurs, 9/8, 12pm-1:30pm
Juneau — In-Person
—OR—
Fri, 9/9, 1pm-2:30pm
Webinar | REGISTER

Engaging People Living with Dementia
Tue, 9/13, 3pm-4:30pm
Webinar | REGISTER
—OR—
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
—OR—
Tue, 9/20, 1pm-2:30pm
Mat-Su — In-Person

Creating Moments of Joy
Wed, 9/21,
Fairbanks — In-Person

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

Mind Aerobics™
12-week course meeting twice per week
For Alaskans worried about Memory Loss who want to keep their mind fit and engaged.

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

Mind Works™
Mon & Wed, 8/7–11/2, 1pm–2 pm
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.