



Alzheimer's Resource of Alaska

Fall 2014
Volume 33
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Vision to Reality **Person Directed Care Takes Center Stage in Upcoming Anchorage Conference**

“The strange gift of Alzheimer’s is that it teaches us how to be here, now.” International authority on eldercare and geriatric medicine, Dr. Bill Thomas, is passionate in declaring this observation about a disease that seems anything but a gift giver.

Healthy minds, bodies and relationships change with every passing day, month and year – a readily accepted fact of life. And yet there is an undeniable human yearning to maintain the status quo, to freeze time and enjoy the comfort that comes with stability and predictability.

This urge to maintain the status quo can be especially frustrating in caring for a loved one with Alzheimer’s Disease or related dementia (ADRD). The gradual deterioration of memory, identity and personality can be a searingly painful process to witness when that transformation takes place in a loved one.

Dr. Thomas has made a name for himself in proclaiming a simple, healing truth for those caring for a person living with ADRD: “Be here, now. The person you love is.”

Loved ones may no longer be

the people we want them to be, or remember them to be – but their inherent personhood is a reality and a gift to be treasured in the moment.

Person-Centered care takes into consideration the needs, preferences and lifestyles of the individual. Similarly, Person-Directed Care promotes decision making and choices by the individual.



Person-Directed care is not a new concept, but it is often overshadowed by concerns, strategies and motivations that are centered on the disease and not the person.

Education Director for Alzheimer’s Resource of Alaska, Lisa Wawrzonek and her team of Education Specialists organized the upcoming: ***Vision To Reality Conference*** in order to present Person-Centered/Person-Directed care as a real set of practices and strategies that improve quality of life.

Those living with ADRD obviously benefit from Person-Centered

care, but less apparent is the tremendous difference it makes in the lives of caregivers and loved ones.

Northwestern University Professor Ken Paller, authored a new study in the American Journal of Alzheimer’s Disease and Other Dementias on the effects of Person-Centered care for both patients and caregivers.

“We saw lower depression scores and improved ratings on sleep quality and quality of life for both groups. After eight sessions of this training we observed a positive difference in their lives.”

There can be resistance to discussing issues surrounding “the whole person” in terms of caregiving because some aspects of personhood create discomfort.

Sexuality, hygiene and differing cultural norms can be tricky in any context, let alone discussing these topics in terms of parents, grandparents and loved ones with diminished mental capacities. But in recognizing we are greater than the sum of our parts and that we are not defined by a diagnosis,

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Toll Free within Alaska
(800) 478-1080

www.AlzAlaska.org

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Letter from the Executive Director

In 1983, President Ronald Reagan designated November as National Alzheimer's Awareness Month. Thirty-one years later, Reagan's presidential decree is still effective in raising awareness and understanding of Alzheimer's disease. But it was President Reagan's letter to the American people in 1994 that truly galvanized the world's attention – in it he shares his own diagnosis of Alzheimer's disease.



The stark truth is that all too many Americans and citizens of the world become aware of the disease because of its sudden and direct effects on a loved one. A diagnosis of Alzheimer's disease brings with it an awareness of the disease that is both inescapable and ever-present. Campaigns for "Awareness" are more precisely an attempt to educate the public so that we might draw nearer to that day when a cure is found. Only then can this very same public be spared the heartbreaking awareness that comes in living with Alzheimer's disease.

In addition to the support groups and education programs that Alzheimer's Resource of Alaska spearheads, we are also at the forefront of creating greater awareness of Alzheimer's Disease and Related Dementias (ADRD.) We are proud to be the organizer and host for the upcoming ***Vision to Reality Conference*** at the Egan Center this November 12th and 13th. The Conference will bring together an impressive array of experts, caregivers and educators in the field of Person-Directed Care. Research has shown that caregiving that considers the whole person increases the quality of life for those living with ADRD and their loved ones.

We are currently holding two contests meant to inform, inspire and unite Alaskans living in urban, rural, small and large communities throughout Alaska. The Unity Quilting Bee calls on participants to submit colorful designs that represent their community and will be sewn into a larger tapestry – a literal stitching together of caregiving stories from across our great state. We are also accepting entries to our Writing Contest, whose theme is 'Celebration' – a literary sharing of those large and small moments that have enriched the lives of Alaskan families, caregivers and those living with ADRD.

We are also pleased to introduce two new support groups, *Mrs. Fixit* and *The Gentleman's Cooking Club*, in an attempt to aid those who may be taking on unfamiliar tasks around the house in support of their loved one. More information on the two contests and all of our programs can be found on our webpage at alzalaska.org.

We look forward to the Fall season and the changes it brings, including a greater awareness of ADRD and continued commitment to unite Alaskans and ensure quality of life until a cure is found.

Best Regards,

Executive Director

Alzheimer's Awareness: Then and Now

One in nine Americans over the age of sixty-five is living with Alzheimer's disease. The numbers speak for themselves – somebody you know is affected by the disease.

Paradoxically, creating awareness about Alzheimer's disease is no easy task. President Ronald Reagan designated November as National Alzheimer's Awareness Month in 1983, and while we have come a long way since then in terms of recognition and diagnosis of the disease, there is still no cure.

The pervasive and devastating nature of the disease creates an urgent need for greater awareness. Education and comfort for those affected by Alzheimer's disease come on the heels of greater awareness – but equally important is a funding increase for research and innovations in caregiving.

As obvious as it may seem, without a name for a disease there can be no awareness of that disease. It has been 99 years since Dr. Alois Alzheimer passed away and lent his name to the disease he helped identify.

Practicing in Frankfurt, Germany in 1901, Dr. Alzheimer became particularly obsessed with a fifty-one year old patient suffering from memory loss, delusions and temporary vegetative states.

Her name was Auguste Deter and upon her death in 1906 she was the first person ever diagnosed

with Alzheimer's disease.

Records of Dr. Alzheimer's examination and initial interview of Mrs. Deter still survive:

How old are you?

-Fifty one.

Where do you live?

-Oh, you have been to our place?

Are you married?

-Oh, I am so confused.

Where are you right now?

-Here and everywhere, here and now, you must not think badly of me.

A heartbreaking, 113 year old medical record that remains all too familiar today. If he were still alive, Dr. Alzheimer might be surprised to learn that the condition he referred to as the "Disease of Forgetfulness" has become known to the world by his namesake. But perhaps more surprising, is that a century after Dr. Alzheimer's death, Americans are largely unaware that the disease is the fifth leading cause of death due to illness in the United States.

Marking each November as National Alzheimer's Awareness Month certainly raises the profile of the disease and helps focus attention on efforts to combat it. As attention spans grow shorter and demands on our time increase, finding ways to disseminate the essential message of Alzheimer's awareness requires persistence,

imagination and money.

The recent Ice Bucket Challenge dreamed up by the non-profit Amyotrophic lateral sclerosis (ALS) Association was a home-run in terms of raising money and awareness for a devastating illness. Thousands of videos of participants dumping ice-water over their heads and challenging others to do the same were part of a global internet sensation. The result was a campaign that reached millions and raised over \$100 million dollars. Replicating the Ice Bucket Challenge phenomena is unlikely, but harnessing the power of social media and celebrity for a good cause are components of a winning formula.

One of the challenges in raising awareness of Alzheimer's disease is the perception that it is a problem confined to the elderly or that it is simply a normal part of aging.



Funny man Seth Rogen testifies to Congress about Alzheimer's awareness

Comedian and film star Seth Rogen is known for off color, juvenile oriented performances that have earned hundreds of millions of dollars in
(Continued on next page)



ALZHEIMER'S AWARENESS TIMELINE

- 1906 - Dr. Alzheimer describes the symptoms disease that will bear his name.
- 1910 - Alzheimer's Disease is used for the first time in a medical textbook.
- 1974 - Founding of the National Institute on Aging
- 1976 - Alzheimer's Recognized as most common form of dementia
- 1980 - Alzheimer's Association Founded
- 1983 - Declaration of Alzheimer's Disease Month and the founding of Alzheimer's Resource of Alaska
- **1984 - Alzheimer's Resource of Alaska established**
- 1991 - Alzheimer's Disease Cooperative Study established
- 1994 - Former President Reagan announces Alzheimer's diagnosis
- 2003 National Alzheimer's Disease Genetic Study recruits participants
- 2008 International Society to Advance Alzheimer Research and Treatment established
- 2009 - President Obama signs National Alzheimer's Project Act into law

...Awareness

worldwide box office revenue.

But he is fast gaining a reputation as a powerful advocate for Alzheimer's awareness. Rogen favorably impressed many who had not seen his films when he offered funny and heartfelt testimony before Congress to discuss the hardships and pain that Alzheimer's disease has brought to his own family. Rogen gained awareness of the disease when his mother in law was diagnosed with early onset Alzheimer's.

Rogen and his wife went on to form *Hilarity for Charity*, a non-profit that raises money and creates a next generation of advocates for Alzheimer's disease.

Hilarity for Charity began as a fund raising variety show featuring top flight musicians and entertainers. Now in its third year, the organization has grown to include shows produced on college campuses around the nation.

Hilarity for Charity is determined to reach the Millennial Generation,



Nelson Dellis's Alzheimer's awareness non-profit organization

twenty-somethings who are all too unaware of the threat that Alzheimer's disease poses to themselves and the loved ones in their lives.

Rogen is not alone in his novel

approach to creating awareness amongst a new generation that may not be familiar with Alzheimer's disease.

Nelson Dellis lost his grandmother to Alzheimer's disease and has dedicated his peculiar combination of talents and passion to crusade on behalf of finding a cure.

Dellis is what is known as a "memory athlete". He is the reigning and three times USA Memory Champion – a discipline that tests the ability of entrants to memorize random strings of numbers, word lists, dates and the exact order of a deck of cards all within a matter of minutes.

Watching the gradual degradation of his beloved grandmother's memory made a tremendous impact on Dellis. With his grandmother as an inspiration, Dellis founded a non-profit whose mission it is to raise Alzheimer's awareness.

His organization is called *Climbing for Memory*, a reference to his incredible skills of memorization and a lifelong passion for mountaineering. In summiting mountains around the world, including Denali, and speaking about the precious nature of memory - Dellis is on a relentless campaign to inform and raise money on behalf of Alzheimer's research.

The hundred year quest to understand, treat and cure Alzheimer's disease began in a doctor's office in Frankfurt, Germany. The journey continues today and relies on caregivers, doctors, researchers and organizations striving to make the world stand up and notice that there is still much that needs to be done.

Be Our Guest for the Alzheimer's Resource of Alaska's 30th Anniversary Celebratory Dinner and Silent Auction!

SATURDAY, OCTOBER 25, 2014
Doors to Open at 6:00 PM

ALASKA NATIVE HERITAGE CENTER
8800 HERITAGE CENTER
ANCHORAGE

RSVP: Lorraine or Angela by October 15th
lguyer@alzalaska.org / aanderson@alzalaska.org
907.561.3313

WRITING CONTEST

Deadline for receipt of entries is 5:00PM November 21! Winner announced on December 5th

Celebrations mark special moments in our lives. We at the Alzheimer's Resource of Alaska are proud to be celebrating 30 years of service in the State of Alaska. In an effort to create greater awareness amongst individuals of all ages and backgrounds, we encourage you to enter our writing contest. This year's theme: CELEBRATION. Alaskans affected by Alzheimer's disease or related disorders, Alaskan elders and Alaskan caregivers - we invite all Alaskans to submit an essay that expresses your particular way of celebrating life's great and small moments. GRAND PRIZE WINNER: 40,000 miles on Alaska Airlines. Visit our website at ALZALASKA.ORG for more contest details, guidelines and prizes.



Mat-Su Valley Goodness

The Mat-Su Valley area has one of the fastest growing populations in Alaska. The region is fortunate to be served by an amazing team of women keeping pace with the growing needs of those affected by Alzheimer's and related dementias (ADRD). Alzheimer's Resource of Alaska is rightly proud of the work the "Valley Girls" perform week in and week out on behalf of the community. Linda, Melinda, Janice, Jennifer and our newest staff member, Lindy, are making the Valley and our state a better place. In addition to the incredible staff, the Mat-Su office is a first class facility featuring a brand new training room, new programs intended to meet educational and in-home service needs. Join us for one of the many upcoming, free ABC presentations or come and experience the newest program on our roster: the Virtual Dementia Tour (Palmer on November 6th.). Caregivers, family members and those living with ADRD are in good hands in the Mat-Su Valley.

A Night to Remember

On September 20th, for the fifth year in a row, **The New 35 Plus Singles Club** presented: ***A Night to Remember***, a fund raiser benefiting our organization. Couples danced cheek-to-cheek, enjoyed delicious food and walked away with door prizes. The event was a wonderful success due to the club and the sponsors of the event: Arctic Epoxy Flooring, Alaska Chocolate Fountains, Alaska Water Technologies, Fred Walatka & Associates, Silver Bay Seafoods and Kool 97.3 FM. Thank you for being our partners in the community and on the dance floor.



Dressed up and ready to dance



Vision to Reality

(from cover story)

we can improve the quality of life for those living with ADRD.

The *Vision to Reality Conference* will feature breakout sessions such as *Sexual Expression and Older Adults*, *Culture: Embracing Diversity* and, *Sexuality and Diversity: The LGBT Experience*. These sessions will be led by Alaskans for Alaskans – a fitting recognition that Person-Directed care needs to be centered on the particular identities of those being cared for.

In assembling the agenda for the *Vision to Reality Conference*, Wawrzonek could think of no more eloquent spokesperson or practitioner of Person-Directed care than Dr. Bill Thomas. For years, he has been championing and honing the philosophy of treating elders as individual persons whose physical and emotional needs cannot be compartmentalized or ignored.

Thomas is the pioneering force behind the global non-profits *The Eden Alternative* and *The Green House Project*; both of which are reshaping traditional notions of eldercare. Dr. Thomas has turned antiseptic, dreary nursing homes into vibrant centers of care and companionship. In his words, “The boomers are creeping toward elderhood, and I aim to help explain the terrain. The ‘new’ old age is a time of strength and growth and

development and engagement.” Throughout Day One of the conference Dr. Thomas will address attendees in two sessions as he poses the questions: *What Are Old People For?* and *What do Elders Teach Us?*

Improving the quality of life of our most vulnerable citizens will require systematic and organizational transformations.

Jill Vitale-Aussem draws on a twenty year wealth of experience in leading senior living organizations through cultural transformations that seek to improve the lives of elders. Her inclusion in the *Vision to Reality Conference* emphasizes the underlying desire that led Wawrzonek to organize the event: to empower professionals, family

members and those living with ADRD to continue the vital pursuit of lives worth living.

For conference information and registration go to: alzalaska.org

VISION TO REALITY Conference Sponsors

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Vision to Reality featured speakers



Dr. Bill Thomas



Julia Vitale-Aussem

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Alzheimer's
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Classes around the state

For information on any of these classes or programs visit www.AlzAlaska.org/events or contact the office nearest you.

ANCHORAGE

1750 Abbott Rd., 561-3313

Being a Decision Maker

10AM-11:30PM or

5:30-7:00PM

Monday, October 13th

OWL PRESENTATIONS DEMENTIA CARE SERIES

Loussac Library Public
Conference Room/Anchor Point
Library/Craig Library

- **Communicating with our Elders**
10:00-11:30AM
Saturday, October 18th
- **Activity Planning!**
10:00-11:30AM
Saturday, November 8th
- **Behaviors that Challenge Us**
10:00-11:30AM
Saturday, December 6th

ART LINKS

Fridays, 11AM-Noon

JUNEAU

3225 Hospital Drive, 586-6044

- **Behaviors that Challenge Us**
5:30-7:30PM
Tuesday, October 28th
- **Caring for the Caregiver**
5:30-7:30PM
Wednesday, November 19th
- **Art Links**
Thursdays, 10:30-11:30AM

COPPER RIVER BASIN

Glennallen Senior Center, 822-5620

- **Fountain of Youth, Brain Games & Other Activities**
1:00-3:00PM
2nd Friday of the Month
- **Brain Fitness**
"Senior Scribblers"
1:00-2:00PM, Last Thursdays

MAT-SU VALLEY

10355 E. Palmer-Wasilla Hwy.

746-3413

- **The What, How and When of Assisted Living**
10-11:30AM OR 6-7:30PM
Friday, October 17th
- **When Forgetfulness Becomes a Disease**
1-2:00PM OR 5:30-6:30PM
Wednesday, November 19th
- **Remember When**
Noon-1:30PM or 6-7:30PM
Tuesday, December 9th
- **Being a Friend**
Noon-1:30PM or
6-7:30PM
Tuesday, December 16th
- **Art Links**
Fridays, 1:00-2:00PM
- **Mind Matters**
10:30AM - NOON
Wednesdays,
Screening Required

FAIRBANKS

565 University Dr., Suite 2
452-2277

- **Bathing without a Battle**
5:30-7:00PM
Tuesday, October 21st
- **Behaviors that Challenge Us**
5:30-7:00PM
Tuesday, November 18th
- **The What, How and When of Assisted Living**
5:30-7:00PM
Tuesday, December 16th
- **Art Links**
Thursdays, 1:30-2:30PM

PROFESSIONAL WEBINARS

Free / Registration Required

email Amber at asmith@alzalaska.org

- **Understanding Adult Guardianship**
12-1:00PM
Tuesday, October 28
- **Continuing the Conversation: Sexual Expression & Older Adults**
12-1:00PM
Tuesday, November 18

FAMILY CAREGIVERS WEBINARS

Free / Registration Required

email Gay at gwellman@alzalaska.org

- **Behaviors That Challenge US**
Thursday, November 6th
7-8:30PM
- **Holiday Connections**
Thursday, December 11
7-8:30PM

MEMORY SCREENINGS

Anchorage Office - 11/18, 1-5pm

Palmer Office - 11/19, 2-5pm

Juneau Senior Center - 11/19, 10:30am - 1:30pm

Juneau Office - 11/18, 9:00am - 5:00pm

Fairbanks Office - 11/17, 9:00-5:00pm Call for appoint.

VIRTUAL DEMENTIA TOUR - Registration Required

Anchorage Office - 11/6 from 1:00-4:00pm

Palmer Office - 11/6 from 10:00am - 2:00pm

Juneau Office - 11/3 from 1:00-4:00pm

Fairbanks Office - 11/7 from 12:00-4:00pm

Kodiak - Location TBD, 11/19 from 1:00-4:00pm

Homer Senior Citizens - 12/1 from 2:00-5:00pm

Dillingham - Grandma's Place 10/22 from 1:00-4:00pm



Support Groups around the state

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

| Anchorage | | | | |
|--|--|---|--------------------------|---|
| Alzheimer's Resource of Alaska 1750 Abbott Rd. | General Caregiver General Caregiver | 2nd Thursday 4th Thursday | 12PM-1:30PM 5:30-7 PM | Debbie Chulick 561-3313 |
| Chester Park Cooperative 2020 Muldoon Rd. | General Caregiver | 1st Friday | 10 -11:30 AM | Kim Jung 561-3313 |
| Eagle River | | | | |
| Holy Spirit Episcopal Church 17545 N. Eagle River Loop Rd. | General Caregiver | 2nd Thursday | 6:30-8 PM | Marilyn McKay 561-3313/Linda Shepard 746-3413 |
| Statewide Telephone Support Group | | | | |
| Alzheimer's Resource of Alaska | General Caregiver | 1st and 3rd Wednesday 2-3 PM Dial in 1-877-216-1555, Code 927989 | | Gay Wellman 882-5620 or (800) 478-1080 x6 |
| Fairbanks | | | | |
| Alzheimer's Resource of Alaska 565 University Ave. Suite 2 | General Caregiver | 1st & 3rd Tuesday | 11:30AM-1PM | Joan Adams 452-2277 |
| Homer | | | | |
| Friendship Center | General Caregiver | 2 Thursday's a month | 2:30-3:30 | Mary Jo 235-2295 |
| Juneau | | | | |
| Bridge Adult Day Center 1803 Glacier Highway | Family Caregiver | Call for more information | | Joylynn for INFO at 463-6177 or 866.746.6177 |
| Ketchikan | | | | |
| Southeast Senior Services | Family Caregiver | Call for more information | | Bernice 225-8080 |
| Kodiak | | | | |
| Kodiak Senior Center 302 Erskine Ave. | General Caregiver | 4th Thursday | 12:30-1:30 PM | 486-6181 |
| Mat-Su Valley | | | | |
| Alzheimer's Resource of Alaska Trinity Barn Plaza Mile 2.2 Palmer-Wasilla Hwy. | General Caregiver | 2nd Wednesday | 1-2:30 PM | Linda Shepard 746-3413 |
| Seward | | | | |
| Seward Senior Center | General Caregiver | 4th Thursday | 1-2 PM | 262-1280 or (800) 776-8210 |
| Sitka | | | | |
| Brave Heart Volunteers | General Caregiver | 2nd Wednesday | 12-1 PM | 747-4600 |
| Soldotna | | | | |
| Soldotna Senior Center | General Caregiver | 2nd & Last Tuesday | 1-3 PM | 262-1280 or (800) 776-8210 |
| Sterling | | | | |
| Sterling Senior Center | General Caregiver | 1st Tuesday | 1-2 PM | 262-6808 |



**Alzheimer's
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of Alaska**

30TH ANNIVERSARY

1984–2014

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Support Alzheimer's Resource of Alaska through your workplace!

Workplace giving makes supporting Alzheimer's Resource of Alaska easy for you and helps us provide sustaining support and services to frail elders and their families across Alaska.

You can contribute to us through any workplace contribution program like the Combined Federal Campaign (CFC# 52943), Alaska Community Share or United Way. If Alzheimer's Resource of Alaska is not included in your campaign list, include us in the "other" selection of your list.

Many employers offer matching gift programs, check with your Human Resources department to double your support of our work.