

**1/31/12
PRESENTA-
TION:
ALZHEIMER'S
RESOURCE OF
ALASKA**

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ALZHEIMER'S RESOURCE OF
ALASKA</SUBJECT><COMM>SHSS27</COMM></TARGET>

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TESTIMONY
Joint Session House and Senate HSS Committees
January 31, 2012

My name is Patrick Cunningham and I am a member of the Board of Directors of Alzheimer's Resource of Alaska. I am also an Associate Professor of Social Work in the College of Health, University of Alaska Anchorage.

Thank you for the opportunity of meeting with you to present information regarding Alzheimer's Disease and Related Dementia. Related to this, I wish to thank Senator Bettye Davis for introducing Senate Bill 179 creating missing vulnerable adult prompt response and notification plans. This is similar to the Amber Alert for missing children, but targets adults. Victims of Alzheimer's disease and related dementia have a tendency to wander as one of the manifestations of the condition and are at risk. Just last month in Fairbanks, a 63 year old woman suffering from Alzheimer's Disease froze to death after she became disoriented while driving, ran out of gas, and tried walking several miles to seek help.

A number of University of Alaska Anchorage Bachelor and Master of Social Work graduates are employed by Alzheimer's Resource of Alaska and provide education and support services as well as care coordination. Last July, I attended the Alzheimer's Association International Conference on Alzheimer's disease, in Paris, France.

Attending this Conference were over 5,000 scientists from all over the world who are engaged in a variety of research ventures seeking the causes of the disease and developing treatment interventions. I had the opportunity of reporting on challenges of care coordination in Alaska listing 20 challenges and proposing 20 solutions. Among the solutions was an emphasis on proactive early detection and engagement in services. I learned at the Conference that it is possible to identify individuals who are at risk for the Disease ten years prior to onset with 80% accuracy. The identification of biomarkers that may be measured with brain scans, spinal fluid analysis, blood, and cognitive markers consisting of tests for mild cognitive impairment are methods that are being used. At the Conference, the results of The World Alzheimer Report 2011 provided evidence that early dementia diagnosis, coupled with early intervention, is cost-effective, as the costs of an earlier diagnosis are more than offset by savings from the use of antidementia drugs and delayed institutionalization. Other key findings were

- when people with dementia are well prepared and supported, their initial feelings of shock, anger, and grief often give way to a sense of reassurance and empowerment;
- earlier diagnosis allows patients to plan ahead while they can still make important decisions about their future care and allows them and their families to access timely practical advice and support, as well as to access available therapies that may improve their cognition and enhance their quality of life; and
- most people with early-stage dementia would want to be told of their diagnosis.

The Alaska Division of Public Health conducts the Behavioral Risk Factor Surveillance System (BRFSS). Data are collected on risk and preventive behaviors and chronic disease prevalence that are especially useful for planning, initiating, supporting, and evaluating health promotion and disease prevention programs. Although Alzheimer's disease is listed as the 8th leading cause of death in Alaska and predicted to increase, it is not referenced in the section dealing with chronic disease. The Center for Disease Control Healthy Aging Program has developed an Impact of Cognitive Impairment Module to assess and monitor the public's beliefs about the impact of cognitive impairment. So far, 20 states have added it to the Behavioral Risk Factor Surveillance System. It consists of 10 questions. The CDC has also developed a Caregiver Module to examine various aspects of caregiving. It also contains 10 questions. If the Division of Public Health were to include these modules in the survey, this would provide service providers like Alzheimer's Resource of Alaska with essential information to assist them in health promotion and disease prevention programs.

To date, treatment interventions for Alzheimer's disease and Related Dementia consists of pharmacological and non-pharmacological approaches. Some medication has been found to delay the progression of the disease, if identified early, but not cure it. Among the non-pharmacological approaches are prevention of risk factors, psychological, diet, exercise, and cognitively stimulating activities. Some experts are advocating for a paradigm shift away from the current approach of treating symptoms as they emerge to targeting the disease in its very earliest, preclinical stage. These are individuals with mild cognitive impairment who have not progressed to Alzheimer's

disease. This offers the best opportunity, to date, to prevent or substantially delay the Disease.

A study reported at the Conference that I attended stated that up to 50% of Alzheimer's Disease cases are potentially attributable to 7 preventable risk factors. These include smoking, physical inactivity, midlife obesity, midlife hypertension, depression, diabetes, and cognitive inactivity. This is where interventions to increase education and physical activity and reduce smoking rates and depression could potentially have a dramatic impact on Alzheimer's prevalence over time. At the national level, government action on AD does not reflect the expanding human, social, and economic burden of the disease for American families. Today there are 5.4 million Americans with Alzheimer's disease and by 2050, as many as 16 million Americans will have Alzheimer's and the cost of care will surpass \$1 trillion annually. There is currently no cure for AD and no disease-modifying treatment, so the current best hope lies in identifying prevention strategies.

Psychological interventions target behavioral and psychological symptoms of dementia. The most obvious are agitation, aggression, mood disorders and psychosis. Some examples of interventions are art, music, activity, and validation therapy.

In terms of diet, a study of relatively healthy elderly adults found that those with diets rich in several vitamins B,C,D,E, or omega-3 fatty acids had better cognitive function and less brain atrophy associated with Alzheimer's disease than their peers with diets less abundant in these nutrients. Those who ate a diet rich in red meat and full-fat dairy foods were more likely to get Alzheimer's disease compared to those who ate a diet

consisting mostly of nuts, poultry, fish, fruits, and vegetables. A chemistry professor at UAA has been recently rewarded a grant to study the effect of bog blueberries on dementia. Circumin derived from the spice turmeric reduces amyloidal accumulation and synaptic marker loss associated with Alzheimer 's disease. There is currently a clinical trial underway to determine the effect of the herb sage as a potential treatment for the disease. Sage has been demonstrated to enhance memory and mental function.

Mounting evidence suggests that physical activity may have benefits beyond a healthy heart and body weight. Through the past several years, population studies have suggested that exercise which raises your heart rate for at least 30 minutes several times a week can lower your risk of Alzheimer's. A number of clinical trials are examining the effect of aerobic fitness training on human cognition, brain structure, and brain functioning in older adults. The use of a Nintendo gaming console called Wii Fit is being tested for aerobics, strength training and balance improvement with individuals with a diagnosis of mild dementia. A nurse at the University Of Washington School Of Nursing is evaluating an exercise and health promotion program for older adults with mild memory loss. And lastly, an even more promising program included exercise and mental activity. The participants rode recumbent bikes for an average of 3 rides per week, plus they had a virtual reality display that allowed them to ride in a 3-dimensional landscape and race against a ghost rider based on their own last best performance.

In a group of healthy elderly individuals, researchers found that greater participation throughout life in cognitively stimulating activities such as reading, writing, and playing

challenging games ^{were} ~~was~~ associated with less beta-amyloid deposition in the brain, a hallmark of AD. Other cognitive activities for AD patients is to engage them in activities of recollection which are not only general in nature, but also can focus on memory skills that can be directly helpful to them in activities of daily living, such as where they left a purse or wallet, or what is their living address. These memory exercises are also beneficial to their caregivers, who often get frustrated with the memory deficits of their family member.

One of the functions of the agency's Education and Support Program is to provide education to the health care provider. Since it is the primary health care provider who bears the responsibility for managing most of the AD patients, there clearly is a need to assist these clinicians with best practices guidelines. When best prepared, the provider will be able to make the appropriate diagnosis and, in a timely manner, inform the patient so that crises can be avoided, therapeutic and rehabilitative support can be initiated, and the patient can be adequately informed so that choices can be made for the future while decision-making capability remains. The patient and family face many short-term and long-term decisions that are best made based on knowledge of the disease process, the range of symptom progression, and the ultimate prognosis. This would include making decisions about advance directives to physicians, appointing a durable medical power of attorney, discussing end of life decisions with whoever will be designated as the surrogate decision maker, and future living arrangements. This is where a referral to the agency education and support services is warranted.

In terms of an economy of scale, when you consider the services provided by this program it becomes very cost effective when it may prevent the development of Alzheimer's Disease or delay it resulting in the individual remaining in their home and community for as long as possible, extending their quality of life and remaining out of an assisted living facility or nursing home. If the services the program provides delays for one year a nursing home admission for two clients, it results in a savings of well over \$200,000. When you consider this, the request for \$223,000 additional funding for the grant is a very modest one. Even more funding would enable an even greater outreach program.

**Alzheimer's Disease & Related Disorders (ADRD) - Education and Support Program
Request for Funding Increment – FY 13**

Budget Component: Senior Community Based Grants (2787)

RDU: Senior and Disabilities Services (487)

The **ADRD Education and Support Program** of the Alzheimer's Disease Resource Agency of Alaska provides support and education services **statewide** for people with Alzheimer's disease and related dementias as well as healthcare professionals, service provider agencies and the general public. The program provides outreach, information & referrals, consultations, memory screenings, support groups, and education for professionals and the general public. Through this program's activities the Alzheimer's Resource of Alaska raises public awareness of ADRD (signs and symptoms, diagnosis, healthy behaviors, etc.) which helps reduce the stigma associated with the disease. This program is a portal into the continuum of care and has a tremendous reach considering its very few resources. The Alzheimer's Resource of Alaska has provided these services on-going for 27 years. Overtime, we designed new programs and expanded service offerings to keep up with the population growth and the demand for services.

The senior population in Alaska is growing at a staggering rate and the number of people affected by Alzheimer's disease is growing proportionately. In 1990 an estimated 2,200 people had Alzheimer's disease while today that number is over 6,000 (172% increase).

SDS currently provides a \$127,118 grant for this program. The original grant in 1984 was \$28,838. From FY 92 through FY 08 the grant remained flat at \$115,443. In FY09 the grant was increased approximately 10% to the current \$127,118. In 20 years (FY92-FY2012), the grant was increased once by 10%.

The expectations for the organization for the use of these funds are significant:

- ⇒ Statewide Services
- ⇒ Demonstrated knowledge and expertise in providing education, training and support to caregivers, individuals, service providers and the community about ADRD
- ⇒ Statewide outreach with particular attention to rural and underserved communities
- ⇒ Information, referral and assistance via a statewide toll-free line
- ⇒ Individual and family consultations
- ⇒ Group education and training
- ⇒ Education of professionals and provision of technical assistance to those who are serving ADRD clients
- ⇒ Support groups
- ⇒ Conduct public awareness activities
- ⇒ Maintain staffed offices in Anchorage, Fairbanks, Juneau and the Mat-Su
- ⇒ Maintain a lending library

The Alzheimer's Resource of Alaska supplements this grant with private funds from foundations, corporations and individuals. This amount varies but on an annual basis it can range \$20,000-\$40,000.

In FY 11, the ADRD Education & Support Program served an **unduplicated** 430 individuals and 253 service providers. In addition, the program provided education services to 5,147 individuals statewide (may include some, but minimal, duplication). The following is a sample of the growth in the program in the last 10 years:

Service Levels	FY 2001	FY 2011	Increase in Service Levels
Information & Referral Contacts	6218	28,409	357%
Individual/Family Consultations	270	367	36%
Support Groups	72	153	113%
Consultations for Providers	121	268	121%
Education Activities	62	124	100%
Public Awareness Activities	84	353	320%
Communities Served	61	102	67%

Looking at a longer time span, the increase is even more dramatic. For example, from FY97 to FY11 the number of Information & Referral contacts increased almost 1600%. Given the demographics that we are familiar with, this is not much of a surprise. The demand for services is great now and increasing. The disparity is that in 20 years the State's investment has been minimal with only one increase of 10% in 2009.

The services provided through the *ADRD Education & Support Program* are preventive in nature and give individuals with ADRD and their families tools to preserve independence and maintain persons living at home for as long as it is feasible. Research shows that providing education, counseling and support to caregivers can keep people with ADRD out of nursing homes for an extra 1 ½ years. If this program can keep just ten people out of nursing homes each year, it will save the state more than \$2 million each year. Given the high number of individuals this program serves, it is an extremely cost-effective approach. This program also supports professionals and thus raises the overall quality of care. How many individuals are admitted to API or the ER due to dementia related issues? Are all the staff at these facilities familiar with ADRD behaviors and knowledgeable of how to respond? How many care coordinators are writing care plans for those with ADRD with no understanding of the special needs of these individuals? How many clients with dementia are refused admission back to their assisted living home after a hospitalization or evicted due to behaviors? Training in this very specialized area is an investment in much needed workforce development.

The Alzheimer's Resource of Alaska has done well with the limited resources, however a great deal more work is needed to adequately respond to the demand in services: increased outreach/travel to rural areas, translation of materials to disseminate information to various communities, increased technical assistance and staff training for assisted living facilities and other service providers statewide, increased availability of qualified, professional staff to provide consultations and support to individuals concerned with memory loss and their families, just to name a few of the areas that require attention. With the expected continued growth in this population, additional resources for these basic services need to be allocated to this program. To meet the current program expectations and address the population growth with a reasonable level of effectiveness the **Alzheimer's Resource of Alaska respectfully requests an increase of \$223,000 for the statewide ADRD Education & Support Program for a total grant amount of \$350,000.**

Celeste Hodge

From: Hollie Hendrikson <hollie.hendrikson@ncsl.org>
Sent: Friday, February 10, 2012 1:23 PM
To: Celeste Hodge
Subject: RE: Suicide Presentation

Hi Celeste,

Okay, first for your question on funding. I don't track funding of this issue very closely, but the [Suicide Prevention Resource Center](#) seems to have relatively updated info on funding opportunities within states. I have pasted their information about legislation that involves funding and recent federal funding streams. I hope this helps.

As for the press release, I will be speaking on suicide rates (both Alaskan and US) and I will provide some detail about rates among specific demographic groups. I will also discuss state laws and 2012 legislation that aim to prevent suicide.

A short bio from me:

[Hollie Hendrikson, MSc.](#) Ms. Hendrikson has been a policy analyst at the National Conference of State Legislatures since April 2010 and is responsible for tracking state legislation related to injury and violence prevention including trauma systems. She contributes to multiple publications for state legislators related to policies that aim to reduce injury and violence rates, and address health care access.

I bio will probably not be needed for Laura since she will be accompanying me as my supervisor and trainer and will not be presenting.

And, I do plan on having a power point presentation and I will bring copies of my presentation to disseminate. Please let me know how many I should bring.

I hope this answers all your questions. Please let me know if I have forgotten anything. Thanks!

-Hollie

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From the Suicide Prevention Resource Center

Legislation/Resolutions:

- **2009** – House Bill 123: Extends the statewide Suicide Prevention Council another four years, through June 30, 2013. It also expands the membership of the Council to include a public member as well as representatives from the Department of Health and Human Services and the Department of Education and Early Development.
- **2009** – House Bill 83: Makes appropriations for the operating and capital expenses of the state's integrated comprehensive mental health program. Specifically, the act appropriates \$2,135,700 for rural services and suicide prevention for FY2010.
- **2007** – \$2,241,243 is appropriated for suicide prevention and the rural human services system.

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a friend*

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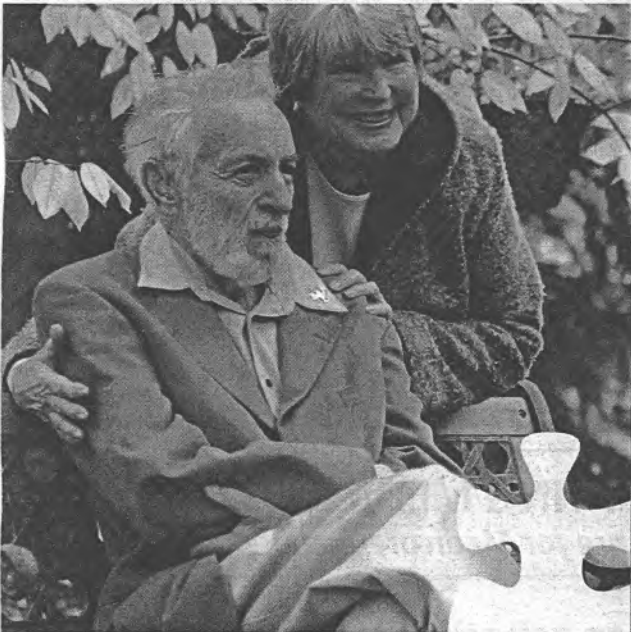


Alzheimer's
Resource
of Alaska

PRESS

Alzheimer's Resource of Alaska

until a cure is found...



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Dear Readers,

Today, in Alaska more than 6,000 people have Alzheimer's.

Alaska has the fastest growth rate of aging population in the nation. From 1990 to 2010, the number of people over age 65 grew 146%. Since the incidence of Alzheimer's disease and related dementias (ADRD) increases with age, the number of people affected is increasing proportionately. When the Alzheimer's Resource of Alaska started in the early 80's as a grassroots effort less than 2,000 Alaskans were affected; since then the number as more than tripled.

To address these demographics, the Alzheimer's Resource of Alaska has expanded the depth of its services to educate, support and care for the individuals affected, their families and communities. The organization serves the entire state of Alaska with offices in Anchorage, Fairbanks, Juneau and Palmer, and we hire workers in local communities to provide home care in rural areas. With the number of people with ADRD expected to double in the next 10 years, we are preparing to address the challenges in the years ahead.

Alzheimer's is a disease that affects the entire family. More than three-quarters of people with ADRD live at home where they are cared for by family and friends. Although most families who care for their aging relatives in the home view care giving as a positive experience, providing 24-hour care is a demanding and draining task. The person with Alzheimer's disease can experience confusion or disorientation, loss of communication skills, agitation or hostility and in the later stages, a need for total care. The caregiver is responsible for all aspects of care and safety for their loved one. Over the course of the disease, watching a loved one's abilities decline from Alzheimer's disease is comparable to a sustained grieving process - a continual loss of the person they once knew.

At the Alzheimer's Resource of Alaska we provide the information that individuals concerned with memory loss are seeking. We help them navigate

the health care system and provide the reassuring support and comfort that lets them know they are not alone. We provide hands-on care in the home to help individuals preserve their independence for as long as it is possible. And, we give family members the knowledge and tools necessary to become skilled

caregivers and preserve their own emotional, physical and mental well-being.

While caring for those affected by ADRD, the Alzheimer's Resource of Alaska does not underestimate the importance of research as perhaps the most important factor in solving the Alzheimer's puzzle. Although there are some medications available that may temporarily improve symptoms, there is still no cure for Alzheimer's.

A great deal of promising research is underway worldwide as many countries are concerned with the financial and social impact this devastating disease will have on society. Right here in Alaska, at the UAF Alaska Basic Neuroscience Program, research is in progress exploring causes and potential therapies for Alzheimer's. Our organization is fully committed to investing in research efforts and this year we established the "Alzheimer's Resource of Alaska Research Fund" with the University of Alaska Foundation to support the excellent work of our research partners here in Alaska.

At the Alzheimer's Resource of Alaska we will continue working hard to ensure respect, dignity and comfort in the lives of those we serve until a cure is found. We hope the next few pages will provide you with some answers about Alzheimer's disease and other dementias and insight into the experiences of those affected. We all know someone who has been touched by this disease and we must begin talking about it not as a myth but as a reality.

Dulce Nobre
Executive Director



Alzheimer's Resource of Alaska

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What is the difference between dementia and Alzheimer's disease?

ONE OF THE MOST FREQUENTLY asked questions is: "What is the difference between dementia and Alzheimer's disease?" Dementia is not a disease itself. It is a term used to describe a number of symptoms that can be caused by various conditions and diseases that affect the brain. Dementia symptoms include a decline and loss of cognitive functions and memory, confusion, behavioral and personality changes in the affected person. Alzheimer's is just one disease that causes dementia.

There are a number of conditions that have similar cognitive effects as Alzheimer's disease. Vascular dementia, Parkinson's disease and Lewy Body dementia are just a few that exhibit many of the same symptoms and are often referred to as "related dementias".

The confusion between dementia and Alzheimer's is because the terms are often used interchangeably even though dementia can have a number of other causes. It is even possible for a person to have more than one form of dementia at the same time. One of the most common combinations of dementias is referred to as Mixed dementia, which is the combination of Alzheimer's disease and Vascular dementia.

Alzheimer's disease (AD) is the most common cause of dementia. It affects approximately 6,000 Alaskans and 5.4 million people nationwide. It attacks the brain and over time causes serious mental and physical decline, eventually leading to death. The disease is typically associated with memory loss but symptoms also include a loss of language and thinking abilities as well as changes in personality and behavior. These changes happen over time and symptoms come on gradually.

In Alzheimer's a buildup of Amyloid plaques and tau-containing neurofibrillary tangles keep the brain from making connections. With AD these buildups typically start in the region of the brain that concerns memory. As the disease progresses, more blockages are formed and connections are continuously inhibited. Simultaneously, there is a decline of Acetylcholine, a chemical responsible for transmitting messages from one brain cell to the next. Eventually nerve and brain cells begin to die causing the brain itself to shrink.

Causes of Alzheimer's are still unknown for the majority of cases. It is thought that a combination of genetic, environmental and life-style factors may lead to the disease but there is no definite answer. There is one exception, families who have a history

of early-onset AD (AD before the age of 65), can pass a genetically transferrable gene mutation to their children. Mutations found in the APP, PSEN 1 or PSEN 2 genes, if inherited will cause Early-Onset Familial Alzheimer's (EOFA). However this genetic link is extremely rare and only found in a small portion of all Alzheimer's cases.

There is still much to learn about Alzheimer's disease and other forms of dementia. Medications have been developed to temporarily slow symptoms in those with progressive mental impairments, but eventually these disorders catch up. Until a cure is found, Alzheimer's Resource of Alaska is dedicated to providing education, support and services to all individuals affected by Alzheimer's disease or a related dementia.



RELATED FORMS OF DEMENTIA

include:

- Vascular dementia
- Parkinson's disease
- Lewy Body dementia
- Frontotemporal dementia
- Creutzfeldt-Jakob disease
- Normal pressure hydrocephalus

HEALTHY HABITS

Recent research suggests that leading an overall healthy lifestyle may lower the risk of developing Alzheimer's disease and related dementias. Healthy habits include:

- Exercise
- Engaging in mentally stimulating activities
- Eating well
- Staying socially active

Ten Warning Signs

Alzheimer's disease is not normal aging. Alzheimer's disease is an illness which leads to a loss of cognitive abilities (i.e. memory, judgment, reasoning, language, perception, etc.). Symptoms usually occur in adults 65 years and older, although people in their 30s, 40s, and 50s may also be affected. Alzheimer's disease is the most common form of dementia. However, it is not the only cause of dementia.

Check for these 10 warning signs. If you find yourself answering yes to a number of these questions contact a doctor or the Alzheimer's Resource of Alaska.

Do You Or A Loved One Have...

1. Recent memory loss that affects daily living skills?
2. Difficulty performing familiar tasks?
3. Problems with language?
4. Disorientation of time, place?
5. Poor or decreased judgment?
6. Problems with abstract thinking?
7. A problem frequently misplacing things?
8. Sudden changes in mood or behavior?
9. Dramatic changes in personality?
10. Significant loss of initiative?

Mind Matters

A program for those with early memory loss



“I LIKE TO BE AROUND PEOPLE who believe in me,” John announced. The focus of the morning’s discussion among group members of Mind Matters, an early memory loss support program, was whether or not to tell others about a medical condition affecting their brain. Many confessed to remaining silent on such disclosure, fearing that friends and neighbors might begin treating them differently. Others like Tim say they have had to because it is now obvious that something is wrong.

This group meets once a week. The men and women sitting around the room are living with various degrees of memory loss. Some have been diagnosed with Mild Cognitive Impairment (MCI), others with Alzheimer’s, Tim has Parkinson’s. They come together week after week to connect with others experiencing similar challenges and engage in activities that connect them to the community.

Mind Matters is an education and support program for individuals with early memory loss facilitated by the Alzheimer’s Resource of Alaska. The program offers a forum for people like Tim and John with early memory loss to share information, understanding, camaraderie, humor and hope with each other through discussions and activities.

Today is a discussion day and the group continues to talk about how there are friends and neighbors who find it difficult to remain in touch with a person living with memory loss and other cognitive changes. Probably because they don’t know how to react or have fears that they won’t be able to communicate. Discussions for the group typically revolve around topics like these as well as understanding diagnosis and the impact of the disease, managing lifestyle and relationship changes and preparing for the future.

According to Marilyn McKay, program facilitator and education specialist at the Alzheimer’s Resource of Alaska, “This is definitely a time of challenge in the lives of group members and those closest to them. It’s a time to sort through feelings of fear, anger and frustration. By group members sharing

with family, friends and the community they feel less alone. The program is a process of learning and sharing among accepting and understanding peers. It’s also a reminder that life continues with all of its ups and downs.”

For Tim, “[The program] is about learning what other people are doing and how they deal with it. People are airing their inner most feelings and pieces of information here and there to help.”

Program participants engage in a variety of activities including writing poetry, volunteering to bag food for the Children’s Lunchbox Program, listening to guest speakers and on one chilly spring morning even bird watching at Westchester Lagoon.

“Having a variety of activities provides opportunities to continue to be creative, help others, learn something new and relax in the company of friends” says McKay.

These kinds of early memory loss programs were pioneered by Robyn Yale, LCSW, of San Francisco in 1986, and are now being replicated throughout the world. Her model combined education and support to better serve individuals living with early memory loss and their families.

Research has shown that groups like Mind Matters play an important role in reducing the isolation experienced by those living with early memory loss. Sharing personal experiences, helping others living through similar experiences, learning about memory loss, ways of coping and caring for self, along with the encouragement received from others eases individual distress and loneliness.

But research doesn’t capture the reason these participants come back week after week. Jim comes for a shared feeling of learning and hopefulness. “I’ve heard there is no way out of this. I can’t accept that. There has to be something. I come to learn from others.” And he will as he shows up weekly to the new discussions and activities of Mind Matters.

I AM

I am Long Island, Seattle, Los Angeles and Boston, North Dakota, Alabama, Kansas and Missouri, I am Rocky River, Ohio.

I am father and son, husband and grandpa, I am mother, daughter and wife, I am family.

I am a gardener
bird watcher
reader of books
cross-country skier
I am one who likes to patschke.

I am honesty and integrity,
caring and compassion.
I am love.

—Members of Mind Matters
An Early Memory Loss Program of
the Alzheimer’s Resource of Alaska
September 6, 2011

What Is It Like to Have Alzheimer's Disease?



ABOUT THE AUTHOR:

Dr. Richard Taylor, a retired professor and psychologist, was diagnosed with dementia of the Alzheimer's type a decade ago. Since his diagnosis, he has been thinking, speaking and writing about his condition as well as advocating for those with early-stage and early-onset Alzheimer's disease.

FEBRUARY 24TH

DR. TAYLOR WILL BE

SPEAKING at Alzheimer's Resource of Alaska's Winter Workshop. The workshop will be held at the BP energy center and those that attend will have an opportunity to talk to Dr. Taylor and Eden Mentor, Dr. Allen Power.

This is an excerpt from Dr. Richard Taylor's book: Alzheimer's From the Inside Out a collection of essays he has written since his Alzheimer's diagnosis in 2001.

WHAT IS IT LIKE to drive your car from Houston to Anchorage? The answer depends on many things: the type of car you will drive, the age of the car, how well you maintained it, where you are in your trip, if others are helping you with the drive, if you have enough gas or access to a gas credit card, if you have accepted the fact you must drive to Anchorage, whether or not you are afraid of arriving in Anchorage.

What is it like to have Alzheimer's? This, too, depends on many things: Do you have an existing group of individuals who are committed to your well-being? Are you a proactive or a reactive person when it comes to dealing with doctors, our health insurance company, and yourself? Where do you live: Houston, Texas, or Houston, Nigeria? Do you have insurance? Especially long-term care insurance? Does your culture and economic class encourage and promote younger generations taking responsibility and care of their family's older generations? There are dozens of important factors outside of yourself that will directly and significantly influence you and your inner experiences with the disease.

After meeting, speaking, and corresponding with hundreds of people who have Alzheimer's, I am convinced there is no universal answer to the question, "What is it like to have Alzheimer's?"

Since the disease process unpredictably and seemingly randomly destroys various cognitive processes and undermines the basis of most all understanding and memory, each person has a unique and personal way of dealing with the rate, the degree, and the various components of the syndromes we attribute to Alzheimer's disease. Neurologists who tell us they understand the disease because they see 4 or 40, or 400, individuals with Alzheimer's does not mean they understand me or you. Just as there really is no single "average" person, there is no meaningful "average" Alzheimer's disease experience.

I was diagnosed with dementia of the Alzheimer's type two years before I wrote this piece. I imagined, maybe hoped, that some day I would wake up and a heavy velvet curtain would have fallen during the night. I would wake up to a world where I could see shapes but not enough details to know what or who they were, sort of like Plato's flickering shadows on the wall produced by the fire on the cave floor.

Instead, right now, I feel as if I am sitting in my grandmother's living room, looking at the world through her lace curtains. From time to time, a gentle wind blows the curtains and changes the patterns through which I see the world. There are large knots in the curtains and I cannot see through them. There is a web of lace connecting the knots to each other, around which I can sometimes see. However, this entire filter keeps shifting unpredictably in the wind. Sometimes I am clear in my vision and my memory, sometimes I am disconnected but aware of memories, and other times I am completely unaware of what lies on the other side of the knots. As the wind blows, it is increasingly frustrating to understand all that is going on around me, because access to the pieces and remembering what they mean keeps flickering on and off, on and off.

Thanks in large part to my family caregivers, I am still functioning in the non-Alzheimer's world. I drive, I learn (although I seem to forget much of what I learn), I teach, I love, I mostly understand—but not all the time, and not always the way others do. It is a constant effort to look around the lacy webs and to have to put effort into understanding and doing things that came naturally but a few months ago (cooking, reading, driving to a new store, remembering the recent past). Some activities hide beyond the knots and rarely have clarity (arithmetic, reading a watch, remembering what I just read). It is not a lot of fun, but I can still do it!

Does the disease increasingly dominate my life, or has the disease insidiously and largely unconsciously become a part of my life?

Does the chicken come first, who I am?

Does the egg come first, Alzheimer's disease?

Today, but not yesterday, I firmly believe: Individuals have a cold, have cancer, have the measles. Alzheimer's has the individual. Ask me again tomorrow! I am trying to be rational and realistic, using tools that are rusting and increasingly out of sync with each other. In my writings you will feel me leaning one way in one paragraph (I am in a war with this disease and I will go down fighting. This is an opportunity for me to grow in ways few people have an opportunity to experience), or another way (I'm mad, I'm sad, and I feel sorry for myself. Why won't others join my self-pity party?).

My writings don't offer answers, just my own observations from my own increasingly unsure perspective.

Tips on being a friend

Talk to me

Please don't direct all your conversation only to the person who is with me.

Listen to me

I may have difficulty finding the words I need, but I have things to say. Please be patient with me as I share my thoughts with you.

Treat me as you always have

I'm not invisible. I'm not contagious.

Let me help

I have advice, strength, time and a desire to give to others. Please invite me to help you.

Include me

Help me to feel comfortable in small groups by including me in the conversation or activities.

Respect my feelings

At times I can be very emotional. Please stay with me if I want you to, or offer me a quiet space.

Encourage me

Recognize that I'm doing the best I can. Celebrate accomplishment with me.

Do things with me

Please don't assume you have to do everything for me.

Tell me what you would like me to do

Choices can be hard for me. It is much easier for me to say "yes" or "no."

Be positive

I'm going to make mistakes and I'm going to feel bad about that. Accept me for who I am right now and with your positive comments let me know that that is enough.

Tips are adapted from the words of Robert Simpson in Through the Wilderness of Alzheimer's (1999)

Living with Alzheimer's in Nunapitchuk

One family's story

CARING FOR SOMEONE with Alzheimer's is not an easy task but doing so in rural Alaska presents a unique set of challenges. Elsie and Ivan Jacobs live in Nunapitchuk a small Yup'ik village in western Alaska set on the Johnson River about 30 miles west of Bethel.

Elsie and Ivan are life long companions, and Elsie cares for her husband who has been diagnosed with Alzheimer's disease. She is responsible for feeding, clothing and bathing both Ivan and herself with the limited resources available. If it is raining, Elsie will make sure to collect the rain so she can use that water to give her husband a bath later in the evening. Running water is not piped into the homes in Nunapitchuk due to freezing problems. They have a small supply of potable water delivered to the house when needed, so she tries to be conservative.

Preserving water, she only washes clothes on the weekends and starts by soaking them the day before. This loosens dirt so she can finish scrubbing them by hand the following day. Winters can make this chore particularly difficult.

These tasks are a part of daily life for many rural Alaskans without being thought of as an added inconvenience. But when compounded with caring for someone with Alzheimer's disease or related dementia (ADRD) managing what were once routine activities can become nearly impossible.

Elsie was referred to Alzheimer's Resource of Alaska for respite services in August 2010 to help her care for her husband with suspected dementia. Soon after, Alzheimer's Resource of Alaska hired workers to provide Elsie and Ivan with services in the home and started sending the couple incontinent supplies from its loan closet to help with their growing needs.

In December of 2010 Ivan had a stroke and needed more help than was available in the village. Just hearing Elsie talk about it best describes how difficult it can be to get advanced medical care in a village with no roads.

"The nearest doctor is two hours by boat and I don't know how many hours by snow machine" she says.

That is how long it takes her to get to Bethel where the nearest hospital is located. She can take the Kuskokwim River or drive by four-wheeler or snow machine. But in an emergency such as when Ivan suffered a stroke, rural Alaskans need to be medevac'd to a hospital where they have access to more care.



It was during this time Elsie made the decision to keep Ivan at home in the village rather than send him to an Anchorage facility. Aside from the added expenses it would take to relocate Ivan, people with Alzheimer's always do much better surrounded by family, friends and the things they are used to. And as Elsie said, with a few extra hands around the house it has become possible to care for him at home.

Today, two Alzheimer's Resource of Alaska workers provide approximately 17 hours of services per week. These workers help Elsie care for her husband's personal needs and do chores such as heavy lifting, washing and housekeeping. Elsie uses some of this time for her own respite to go to appointments and get some time to herself.

"I need help mostly in the mornings. That is when it is hardest" she says. "They really really help me... I thank god for them."

Elsie will repeat this over and over again. She has no lack of appreciation for the in-home workers that come to her house weekly.

After a diagnosis of Alzheimer's was received in

January, Alzheimer's Resource of Alaska awarded Elsie a mini-grant funded by the Mental Health Trust Authority to periodically send care packages to their home. The packages typically include items she can't get or are astronomically expensive in the village. For example, a package of Depends costs almost \$40 in Nunapitchuk as compared to the \$19.99 it costs in Anchorage. As a retired teacher's aid those are prices Elsie can't afford. Other items include food supplements (ensure, food thickeners, etc.) and rubber gloves. Elsie loves the rubber gloves and will mention them often if asked about what helps her the most (other than her in-home workers).

"I'm doing my best to help my husband" she says.

And she is. Elsie had the courage to reach out for help when she needed it most and, as a result, she and Ivan can continue their life together in the unique yet familiar surroundings of Nunapitchuk.

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Jim Clark

One caregiver's story

EVERY FRIDAY, LIKE CLOCKWORK Jim and Ginny Clark show up at the Alzheimer's Resource of Alaska for Art Links. Jim parks Ginny at the table in front of a white piece of paper on a blue sheet next to a set of water colors and brushes. Ginny is usually the first one in the room as others trickle in to join her for the painting session. She can't really paint anymore but Jim still brings her so she can get out of the house and be around people.

Once Ginny is settled Jim takes a moment to "make the rounds". He pops his head into each office at Alzheimer's Resource of Alaska with opening lines like, "I got a joke for ya..." and "did I tell you the one about..." He knows just about everyone in the building and is sure to collect as many hugs as possible. "I'm a bull-shitter," He says with a big grin, "nowadays they call it a people person."

It has been a long road for Jim and Ginny. In early 2006 the couple found out that Ginny had Alzheimer's. The first time Jim noticed something was wrong was in 2005. He was returning his son's truck they borrowed and Ginny was following him. Her driving was erratic, but at the time Jim didn't know why.

The progression of the disease was slow at first. Ginny continued working for another six months after the diagnosis. But eventually she needed to stop.

"To me it was a real shock about how our life was going to change" said Jim.

They had known a bit about the disease because Ginny's mother, sister and one aunt all were diagnosed. In fact, her mother developed signs in the early 60's and was committed to a mental institution at the time. Jim thinks that this history of the disease in her family is why, after being diagnosed, Ginny was always compliant when he was caring for her. "She knew I was trying to help her" he explains "she was always very receptive".

For Jim, after finding out Ginny had Alzheimer's the hardest part was figuring out what to do and how to go about it. Through this process was how he first made contact with Alzheimer's Resource of Alaska.

"I went to the library at the organization, and talked to a young man who worked there at the time, Tony. Smartest move I've ever done in my life" says Jim.

He went on to take classes and join support groups at the Alzheimer's Resource of Alaska. He even had the organization help him talk to his entire family about Ginny's condition and the care she was receiving.

He did this all for his wife. "I owed it to Ginny, I wanted to, I love that woman, I really do... I just need

to take care of her."

For Jim, there was never any question who would be taking care of Ginny through this difficult time. Years ago when Jim got back from the Korean War she stood by him and helped him through some difficult times. Now it was his turn to do the same for her.

And he has in spite of all the challenges. Jim has learned to take blood pressure, comb her hair and coordinate with doctors and pharmacists. He made sure she ate well, regulated her meds (including the ones she hid in her cheek) and learned to work a roaming monitor. For years he slept with "one ear open".

Later in the progression of the disease, when Ginny got mad at the old lady in the mirror Jim put butcher paper up so she wouldn't be bothered anymore. "You've got to conquer what comes at the time" Jim explains "I don't think people really know what goes on, because it is a 24 hour, 7 day a week job".

But doing these things was not what made the disease difficult for him. Instead it was his constant guilt and concern for doing the right thing. If Ginny got sick his first thought was that it was because he didn't clean her well enough or he had exposed her to it somehow. "Sometimes you feel like you're going under" he says. "The most stressful part is wondering whether or not you are doing the right thing... if there's something else you should be doing. People can tell you that you are, but it doesn't always alleviate the questions you have."

For five years Jim didn't do anything major for himself. His life revolved around caring for Ginny and he had to learn a few coping techniques. While Ginny was still living at home he read a lot. He read for escape. He would get Ginny to bed, then go turn on a light, close the curtain to "read and nibble". According to Jim, finding a way to relax and get your mind clear for 15-20 minutes a day is essential. "You can't do it while

they are there."

At times the stress got so bad that Jim says he just blocked it out. Most of the time, he didn't even realize how much stress he was under. At least not until he got in situations that would remind him, one time he recalls spending 15 minutes tearing the house apart looking for his cell phone. His son-in-law called to get a phone number Jim had stored on the phone. Eventually he realized it was in his hand, against his ear, his son-in-law was waiting on the other end.

Now Jim finds humor in these stories and others. "Ginny was always a very affectionate lady" he recalls. And this showed even as her disease progressed. At times they would be in the supermarket and Ginny would walk up to a complete stranger, arms open and say "Hello, I haven't seen you in a long time." She would hug them tight. All the while, Jim was dancing in the background pointing to Ginny and noiselessly mouthing the word "Alzheimer's". "And usually" Jim says "people would hug her back".

Jim encountered a lot of this kindness from strangers over the years. He is still amazed by how generous some people were no matter her condition. Staff at the Golden Coral and the Village Inn would go out of their way to take care of them and make them feel comfortable.

"Those are the little things that make it all worthwhile" says Jim.

Jim cared for Ginny in the home for five years. Now she is living at an assisted living facility where she can get round the clock care. Jim can visit and take her out whenever he likes as he does every Friday when he takes her to get her hair done and to Art Links just as she liked to do regularly before the Alzheimer's progressed.

"We've had a good life" he says. And before he leaves he asks "Did I tell you the joke about..."

Caregiver Facts

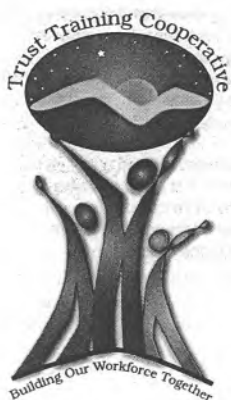
In Alaska, last year over 30,000 family caregivers provided over \$420 worth of unpaid care to a loved with Alzheimer's or dementia.

34 million adults (16% of population) provide care to adults 50+ years.

8.9 million caregivers (20% of adult caregivers) care for someone 50+ years who have dementia.

5.8 million people (family, friends and neighbors) provide care to persons 65+ who need assistance with everyday activities.

Unpaid family caregivers will likely continue to be the largest source of long-term care services in the U.S. and are estimated to reach 37 million caregivers by 2050, an increase of 85% from 2000.



The Trust Training Cooperative (TTC) is a resource that promotes career development opportunities for direct service workers* and their supervisors engaged with Alaska Mental Health Trust Authority beneficiaries, by ensuring that technical assistance and training is accessible.

*Direct service worker is a position that requires a bachelor's degree or less and works at least 75% directly with consumers.

Visit the TTC website at www.trusttrainingcoop.org

The TTC Learning Management System (LMS) provides training opportunities for Alaskan providers who serve Alaska Mental Health Trust Authority beneficiaries.

Visit the TTC LMS catalog of trainings at www.ttcilms.org

TTC Sponsored Trainings: Frontline Leadership Institute, Mental Health First Aid, Hearing Voices that are Distressing, Full Lives Conference for Direct Service Professionals, We Are All Elders in Training Summit, Prevention of Abuse and Neglect of Vulnerable Adults, Learning Networks, and Acquired and Traumatic Brain Injury Case Management Series

Contact the Trust Training Cooperative at 907-272-8270

Caregiving

Do self-care in order to be a healthy caregiver

WHEN TALKING ABOUT ALZHEIMER'S the conversation often focuses on the individual who has been diagnosed. However, it is just as important to recognize the impact this disease has on family caregivers.

Caregiving is a physically, emotionally and mentally draining job and often, the last person to notice the toll it takes is the caregiver himself. The stresses of caregiving build up over time and for many, the job ends up consuming a person to the point where it becomes their sole role in life. They no longer have time to do things for themselves and they are constantly caring for someone else.

Caregivers, more often than not, are family members of a loved one who has been diagnosed. One of the most difficult aspects of caring for a loved one is that it forces people to change roles in ways they never imagined, especially in cases of Alzheimer's. A daughter helps her mother get out of bed, dress, eat and go to the bathroom as her mother once did for her. A husband does the same for his wife, as they once did together for their children.

This role reversal, on top of the financial, physical and logistical responsibilities of caring for someone contributes to caregiver stress and compassion fatigue. Compassion fatigue is a term used to describe someone who cares so deeply for another person that it becomes how they identify themselves. Everything in their lives revolves around the act of caregiving.

According to Lisa Wawrzonek, statewide Education Director at the Alzheimer's Resource of Alaska, this is dangerous because eventually the caregiver starts losing sight of some of their individual qualities. "You are committed to the point that eventually you become blinded to everything else, you are just in the mode of caregiver."

Becoming consumed by the role of caregiving is especially common in people who are considered part of the "sandwich generation". This is a term used to describe people who are caring for their children as well as their parents. They are caught in the middle and their role as a caregiver is pronounced by caring for



two other generations simultaneously.

"It's important to be able to personally identify yourself away from these roles," says Wawrzonek. "You need to pay yourself first. And sometimes to do that, you need to find ways in which you can do self-care in order to be a healthy caregiver."

Doctors agree that to do something solely for oneself can provide an individual with a certain amount of self-care. They recommend taking time away from caregiving each day, even if it only adds up to 30 minutes a week. This allows a person to cope with the stress they are under and recharge for a moment.

"What it all comes down to," says Wawrzonek, "if you are not a happy, healthy caregiver you are not an effective caregiver."

Self-Care Tips *for the caregiver provided by Alzheimer's Resource of Alaska*

Support Groups: It always helps to know that you are not alone. It helps to hear that feelings of guilt, anxiety, anger, frustration and depression are normal. And you can discuss issues you are having with your loved one and get tips from others on how they have dealt with difficult situations.

"You" time: Find something separate from the role of caregiver, something that is just yours. And try to do this activity for at least 15 minutes a day. Read a book after everyone's in bed, take a bath, close the door and tell everyone not to disturb you.

Find yourself again: Ask yourself the question "Who am I?" and find something you can do to reinforce that. This is often a question that can be answered through identifying activities that you once enjoyed doing. For example, gardening, take a moment if you can and garden; at one time, you were not a caregiver, you were a gardener. Go back to that even if it is only for a short time.

Modify: Though you may not be able to take the time to garden anymore, you may be able to take

15 minutes and walk through the park, or visit a nursery. You will still be doing an activity that connects you to things you love, but it will be a modified, more obtainable version of that activity.

Set goals: Give yourself something to look forward to. Maybe it is taking an hour to get your hair done, getting easily through a meal with your loved one, or getting to a class once a month. Whatever you choose, make sure your goals are obtainable and have realistic expectations. Don't set yourself up for failure. Give yourself little successes in life and if you don't make it, it's alright.

Find a happy moment: Find a moment that made you really happy in life. A moment, day or event, that when you think about it, it makes you smile. And hold on to it for a few minutes during the day.

Shut off: Spend some time during the day to clear your mind. Try not to think about all the things you should be doing or will need to do. When something creeps in try pushing it out. Play some music and try it for the duration of the song.

Breathe: Breathe with purpose. Take deep breaths in through the nose and out through the mouth, expanding your stomach. Allow yourself to make noises as you exhale. Flush your system. Release some of those stresses.

Exercise: Research has proven that doing some exercise each day promotes better sleep, reduces tension, increases energy and decreases depression. This can be as simple as going for a walk or doing household chores. The key is to stay physically active.

A glass of wine: If it is something you enjoy, give yourself permission to have that glass of wine at night. Just one glass, any more can disrupt sleep, which is desperately needed for caregivers. But allow yourself to unwind at the end of the day.

Alzheimer's Resource of Alaska Programs and Services



MEMORY SCREENINGS

Free confidential memory screenings are available by appointment and administered at any of our office locations. Memory screenings must be done in person. Call to schedule an appointment at your local office.

CONSULTATIONS

Free confidential consultations are available for individuals, families and professionals to offer guidance in planning for the course of progressive dementia and other medical conditions. Consultations can be held in-person or by phone.

CARE COORDINATION

A service for individuals with physical or cognitive impairments who need assistance locating and accessing community resources for themselves or a loved one. Care Coordination enhances a person's independence, safety and comfort by coordinating the services he or she needs. Available only in the Municipality of Anchorage.

IN-HOME SERVICES

When physical or cognitive limitations make it difficult to remain safely at home, in home services offers a number of resources for clients and their families. Each service is uniquely designed to work with the health and financial considerations of the individual. Services include personal care assistance, chores and respite for family caregivers.

SUPPORT GROUPS

An opportunity for family members and friends to meet regularly for mutual support. Support groups are offered throughout the state of Alaska and we can help connect you with the group nearest you.

ADRD MINI GRANTS

Specifically for those diagnosed with Alzheimer's disease or related dementias, this grant program can assist in obtaining items or services when other funding sources are not available. Confirmation of diagnosis and estimates are required. Applications can be found on the web at www.AlzAlaska.org or www.mhtrust.org.

LENDING LIBRARY

As part of the University of Alaska's Consortium Library, we offer an extensive listing of materials on the topics of dementia, dementia care and diagnosis. Current titles on topics of interest to family and professional caregivers are available at all our locations and a number of resources can be found online at www.AlzAlaska.org.

MIND MATTERS

An educational and support program for those with early memory loss. Participants learn strategies to adapt with confidence and are encouraged to continue an active lifestyle. (See page 4 for a closer look at the program)

ART LINKS

Art Links is a weekly art program that provides a vehicle for self-expression for the memory impaired person. Family and friends are invited to participate. Classes are held in Anchorage and Palmer every Friday.

Education for Family and Friends:

ABC'S OF CAREGIVING

Two-hour workshops are offered every month for people caring for a frail elder or a person with Alzheimer's disease or a related dementia. The "ABC's of Caregiving" classes are free and held regularly in Anchorage, Palmer, Fairbanks, Juneau and the Copper River Basin. Topics include communication techniques, caregiving fundamentals, legal issues and Medicaid/Medicare concerns.

SAVVY CAREGIVER

A family caregiver education program that takes place over the course of 6 weeks, two hours each week. The program focuses on improving the practice of caregiving for both the individual living with dementia as well as the caregiver. Classes offered in Anchorage, Palmer, Fairbanks and Juneau.

Education for Professionals

SAVVY PROFESSIONAL

A one-day workshop that shares essential knowledge, practical skills and visionary outlook in dementia care. For those whose roles require dementia capable leadership, advocacy and mentoring.

DEMENTIA CARE ESSENTIALS

A training program for direct service workers wanting to improve their skills when caring for individuals with dementia. It offers an overview of Alzheimer's disease, understanding the dementia experience, communication skill development and enhancing activities of daily living. Past participants have included: respite workers, personal care attendants, care coordinators, home health workers, adult day, assisted living home, and long-term care staff. Currently offered in Anchorage, Fairbanks, Juneau and Palmer. Classes are also available via video conferencing.

DEMENTIA CARE WORKSHOP

A four hour workshop designed for long term care facilities and large organizations that need the fundamentals of dementia care. Facilities across the state can organize a workshop by calling the education department in Anchorage.

Education for Anyone:

RESEARCH FORUMS

Latest research and discussions on Alzheimer's disease and related disorders are offered with experts from around the nation. The forums are free events open to the public. This November Dr. Joshua Gatson will be speaking about Traumatic Brain Injury and its link to Alzheimer's disease. And in February Dr.'s Allen Power and Richard Taylor will be advocating on behalf of those with ADRD.

MENTAL FITNESS

A social and mentally stimulating program to help improve or maintain mental activity. Classes are held throughout the state at Alzheimer's Resource of Alaska offices and local senior centers.

AWARENESS PRESENTATIONS

For anyone interested in learning more about Alzheimer's disease and related dementias. Alzheimer's Resource of Alaska presents at civic groups, churches, and organizations. Call to schedule a presentation.

FOR MORE INFORMATION

on any of our programs or services contact Alzheimer's Resource of Alaska at one of our statewide offices or call toll free 1-800-478-1080.

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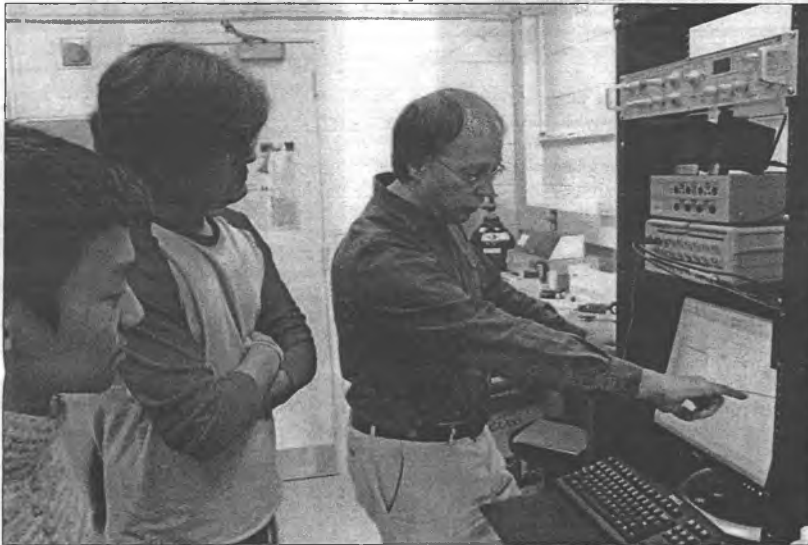
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Mile 2.2 Palmer-Wasilla Hwy
Palmer, AK 99645
(907) 746-3413

You can also visit our website www.AlzAlaska.org for information, program schedules and information.

Many of these programs are made possible with funding by these major grantors: State of Alaska Senior & Disability Services, Alaska Mental Health Trust Authority, Mat-Su Health Foundation, Mat-Su Borough, Fairbanks North Star Borough.

Supporting Alzheimer's Research in Alaska

ALZHEIMER'S RESOURCE OF ALASKA established a fund this year with the University of Alaska Foundation to support promising Alzheimer's research being conducted here in Alaska. This year, the Alzheimer's Resource of Alaska's contribution was designated to Dr. Marvin Schulte's laboratory within the Alaska Basic Neuroscience Program at the University of Alaska Fairbanks (UAF). The lab has made significant progress developing a drug to treat the cognitive effects of Alzheimer's disease.



The Schulte lab has also received funding from the National Institute of Health (NIH) and American Recovery and Reinvestment Act (stimulus funding in 2009) to continue research and development on their lead compound desformylflustrabromine (dFBr). dFBr is a natural product that has been found to increase the activity of an important neurotransmitter that declines in Alzheimer's brains. This compound has the potential to improve cognitive abilities responsible for recalling, retaining and forming memories. Further research may lead to the development of new therapies for Alzheimer's disease.

In 2005 the lab started collaborating with Dr. Richard Glennon, Chair of Medicinal Chemistry at Virginia Commonwealth University to make synthetic variations of the compound. These synthetic variations change the structure of the compound allowing researchers in Schulte's laboratory to determine which properties of the base molecule are important for its therapeutic effects. These variations may enhance the drugs positive characteristics and reduce potential side effects.

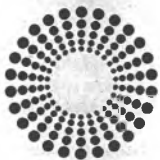
According to Dr. Schulte the excitement surrounding this new drug has been undeniable. "The NIH funded the project on the first submission, which seldom happens." Dr. Glennon started working on changing the compound structure the day after speaking with Dr. Schulte. "We have received a lot of attention at scientific meetings from drug companies and other laboratories interested in this compound," says Schulte.

In order for cells to communicate with one another, a neuron will send a chemical messenger which will result in an electrical signal being discharged on the receiving cell. A person with Alzheimer's begins losing brain function because, for reasons that are not entirely clear, cells in the brain known as neurons start to lose the ability to send and receive signals to one another and ultimately die. Current medications for Alzheimer's act to increase the amount of the neurotransmitter chemicals available but they do not modulate the signal in the unique way the dFBr does.

"This is a very unique drug," says Schulte. "It doesn't activate or inhibit the receptors involved in Alzheimer's disease but instead modulates the signal that is produced".

In laymen's terms, what this means is that the drug dFBr, does nothing unless it is present along with the natural chemical signaling compound in the brain. When put together, the two produce a larger response than then would have been produced without the drug. In other words, dFBr enhances the signal or "turns up the volume" without significantly altering the brains normal control. This is a substantially different way of working than the current Alzheimer's drugs available to patients.

"There is great potential for this drug to help patients in the future" says Schulte. Dulce Nobre, Executive Director of Alzheimer's Resource of Alaska agrees. "Research is the essential piece that will help us solve the Alzheimer's puzzle and someday lead



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A NEW SUPPORT GROUP FOR OLDER ADULTS



Krista Pemberton, LCSW and Maureen Young, LCSW introduce a new support group for older adults struggling with life cycle transitions. Our goal is to provide exceptional behavioral health care across the lifespan with special consideration of the challenges facing older Alaskans.



From left to right: Shane Rideout, Yeganeh Ataian (PhD student), Yanzhou Huang (PhD student), Marvin K. Schulte (primary investigator), Rajesh Khatri (PhD student), Jordan Ross (undergraduate researcher)

to a cure. The research being done in our very own state is providing valuable knowledge to the entire Alzheimer's research community. And while caring for those affected today, the Alzheimer's Resource of Alaska believes in, and is committed to supporting and investing in promising research efforts."

THE FUND

The Alzheimer's Resource of Alaska Research Fund was set up with the University of Alaska Foundation to support the excellent work of our research partners' right here in Alaska. This fund will provide financial support to the Alaska Basic Neuroscience Program to further explore causes and potential therapies for Alzheimer's disease and related dementia (ADRD). The fund is open to anyone interested in contributing to ADRD research.

This year, the fund will allow one graduate student to work fulltime in the Marvin Schulte Laboratory. According to Dr. Schulte, "The ability to have one student concentrate 100 percent of their time in the lab, without distraction, is the most productive way to stimulate research".

Shane Rideout, a third year graduate student at the University of Alaska Fairbanks (UAF) was granted this funding. Rideout received his undergraduate degree in Biochemistry from UAF and went on to pursue a doctorate. He has been working in the lab since 2010 but until recently, has been splitting his time teaching, writing papers, giving presentations and mentoring.

According to Rideout the opportunity to work fulltime in the lab, doesn't just benefit him, "I am incredibly grateful on a personal level for this, but it affects so much more... When we can devote [all]

of our time to research, it is a huge benefit to our productivity."

Over the next year Rideout will be characterizing the interactions of this promising compound, dFBr, as well as developing a new platform to permit more rapid testing of drugs produced by Dr. Glennon. This "high-throughput" type of testing will accelerate the pace of discovery and will potentially benefit other laboratories as well.

THE PROGRAM

The Alaska Basic Neuroscience Program (ABNP) began in 2000 when the University of Alaska Fairbanks (UAF) received one of 12 Specialized Neuroscience Research Program (SNRP) awards. This award from the National Institutes of Health initiated the development and coordination of neuroscience research and education in Alaska. Their goal is to facilitate high-quality neuroscience research and education opportunities addressing identified state and national needs in partnership with local communities, state and federal governments. The ABNP program has received over \$10M in research funding that directly supports neuroscience research in Alaska. In addition to money received from the SNRP program, Neuroscience faculty members are highly productive and receive significant additional support from both NIH and NSF to conduct neuroscience research of relevance to AK. In addition to Alzheimer's research, this includes research into new models of disease and the treatment of stroke, SIDS, Autism, depression and neuroinflammation.

Facts and Figures

Alzheimer's is the **SIXTH-LEADING** cause of death in the country.

Alzheimer's disease is the **MOST COMMON** form of dementia, although there are a number of others with similar symptoms that is why we often refer to Alzheimer's disease and related disorders (ADRD).

Alzheimer's disease is the only cause of death among the top 10 in the United States that **CANNOT BE PREVENTED OR CURED.**



We All Have The Power To Protect you know me

At this stage of my life, I'm lucky to have people who look after me. We all need a support system, especially older Alaskans and people with severe disabilities. Harm comes in many forms: abandonment, abuse, financial exploitation, neglect and self-neglect.

If you know someone who needs help, call Adult Protective Services at (907) 269-3666 or (800) 478-9996 or visit www.hss.state.ak.us/dsds/aps.htm

Geneva Tryck Mortimer, age 93, and daughter Sabra Tryck (right) with Helene Wood who helps care for Geneva. Helene is a Certified Nursing Assistant and volunteer for the Office of the Long Term Care Ombudsman.

The Alaska Commission on Aging
www.alaskaaging.org

The TRUST
The Alaska Mental Health Trust Authority
www.mhtrust.org



Dementia Care Training for Professionals and Paraprofessionals



ALZHEIMER'S RESOURCE OF ALASKA has launched three new specialized programs this year to train professionals and paraprofessionals in the field of dementia care.

The rapidly growing number of people with Alzheimer's disease or related dementia (ADRD) in Alaska has created great demand for a dementia-capable workforce in all areas from home-based services to institutional care. The number of people with ADRD is expected to almost double in the next 10 years, and the shortage of trained personnel will be at a breaking point.

Specialized dementia training is needed because caring for an individual with ADRD requires a unique set of skills for which not all medical professionals or direct care workers are trained. Alzheimer's Resource of Alaska is providing trainings to meet the growing need, accommodating individual workers and organizations by offering three new programs in different locations and venues throughout Alaska.

According to Lisa Wawrzonek, statewide education director of Alzheimer's Resource of Alaska, "These programs are incredibly important because the more professionals trained, the more we promote effective dementia care all-around. People that work with someone who has ADRD need to provide a special type of care, and when they use best care practices in dementia care it makes the experience better for themselves and the individual they're caring for."

The first program launched this year was Dementia Care Essentials (DCE). It was created specifically for direct care workers such as certified nursing assistants, workers in assisted living homes, personal care attendants, in-home workers and care coordinators. The course teaches the fundamentals of dementia, as well as practical skills such as communication techniques, activities planning and best practices in de-escalating difficult behaviors. DCE

is a 10 hour class that takes place over the course of 5 weeks, two hours each week. This format allows participants to study and practice the skills learned each week and bring insights to the following class for further discussion.

The Dementia Care Workshop offers many of the same fundamentals as DCE but in a condensed four hour time frame. This format is typically used by larger facilities wanting to train a number of employees at once about the fundamentals of dementia and basic tools for working with individuals with ADRD. Nursing homes, assisted living facilities, adult day centers and hospitals have been scheduling this workshop in various locations throughout the state.

The third program, Savvy Professional, is an interactive workshop designed for those in leadership roles. The training equips administrators, supervisors, nurses, social workers and attorneys to provide leadership, advocacy and mentoring to others who work with individuals and families affected by ADRD.

So far this year over 200 people have participated in these programs and the response has been extremely positive. The training programs offer continuing education (C.E.) hours to nurses, C.N.A.'s, social workers and attorneys. They are available in Anchorage, Palmer, Fairbanks and Juneau and as of this fall, Education Specialists have begun scheduling Dementia Care Essentials and Savvy Professional in other areas of the state.

In October, DCE will be offered via video conferencing for the first time. The new video conferencing is a result of collaboration between Alzheimer's Resource of Alaska and the Trust Training Cooperative. The first session will be open to professionals in Bethel and Nome.

WINE TASTING FUNDRAISER

NOVEMBER 5

TO BENEFIT ALZHEIMER'S RESOURCE OF ALASKA

The wine tasting will also feature
BLACKJACK, ROULETTE, POKER TABLES
 and a **SILENT AUCTION**.

November 5th at the Alaska Native Heritage Center.

Tickets are available for \$45, \$55, and \$1,000 for VIP seating for eight.

Must be 21 to attend.

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 WINESTYLES AT **907-337-9463**

Dear Lisa

Questions and answers

Dear Lisa,
I recently turned 50 and Alzheimer's has been on my mind more and more lately. Both my mom and my dad developed Alzheimer's later in life and now I am afraid that I might get it. I have heard a lot about Alzheimer's and genetics lately. Is there some sort of blood test I should get done to find out if I am going to end up with Alzheimer's too?

—Genetic Worrier

Good question GW, the short answer is no. What causes Alzheimer's in 99 percent of all cases is still unknown, but age and family history are the two main risk factors. You have probably been hearing about gene mutations in three genes which have been linked to an increased risk of developing Alzheimer's later in life. But it is not a definitive indicator that you will develop the disease. So even if you are tested for these mutations it doesn't mean much. Current research suggests that a combination of genetic and environmental factors cause Alzheimer's and in this case, scientists believe that an overall healthy lifestyle is the best way to prevent the disease.

That being said, Early-Onset Alzheimer's (EOA), which is developed before the age of 65, does not always fall into this category. Only 5 percent of all cases of Alzheimer's are classified as EOA and in only 1 percent of those cases there is a clear genetic link running in families with a long history of EOA. But again, this is very rare and if your parents developed the disease later in life there is no reason for you to be tested.



Dear Lisa,
My mother has been living with us for about seven years and we've been able to take care of her. We feel it is time to ask for help but have really no idea where even to start. Can you point us in the right direction? We'd like to keep her at home if we can.

—Helpless at Home

Dear Helpless,

First, congratulations on caring for your mother successfully at home for so many years. There is a

place to start and I would recommend a consultation with a care coordinator at Alzheimer's Resource of Alaska. A care coordinator is an expert at community resources, services and funding sources. They can help with both short and long term plans and providing options for care for you and your family to choose from. You may feel after getting the information, you can arrange the necessary services but it is also nice to have a care coordinator ongoing to provide an extra set of eyes as well as someone who gets to know you and your loved one. This is helpful in the event of a significant change or decline. Knowing the situation can allow the care coordinator to jump right in with assistance rather than trying to learn from the ground up when you really need action.

Care coordinators know of the resources such as in-home services, adult day centers and companionship services that can provide your family a break, interaction with your loved one and peace of mind all around.

Dear Lisa,

My husband was recently diagnosed with Alzheimer's and lately, he's been asking me about things we did years ago or talking about places where we lived as though we are still there. I try to tell him that we're in Alaska, not Oregon anymore or remind him when these things happened but he gets really angry. How do I keep him calm? And why is he getting so angry at me?

—Unsure what to do

Dear Unsure,

This is a very common scenario so I'm glad you asked this question. Alzheimer's disease is affecting two areas of cognition that cause him to think of past experiences as if they are happening in the present. One is memory and the other is reasoning. Memory and reasoning are two of our cognitive thinking abilities that can be affected or impaired by Alzheimer's disease or related dementia. First, short term memory is affected so new learning will be impaired but individuals hold on to long term memories for a while. The individual begins to regress through his long term memory and those memories come back to him as if they are present reality. This becomes his reality. It then becomes difficult to re-orient the person to our reality or truth because he loses the ability to reason.

Telling a person with Alzheimer's the truth becomes like telling him that he is wrong. Many will react confused, frustrated or even angry because they don't understand. The best thing to do when he starts telling you stories of things that happened years ago is to go with the flow. Validate his stories and maybe try to re-direct him to the task at hand. Use those stories as tools if he becomes agitated. You can say, "tell me about" and bring up one of the stories he can still remember. One positive spin is that these are experiences this disease has not taken away from him yet. And if you need to, don't hesitate to call for a consultation at the Alzheimer's Resource of Alaska. Someone there can help you find other ways of coping to meet your needs as well as your husband's.

Dear Lisa,

I have been taking care of my mother who was diagnosed with Alzheimer's for about a year now and things have been going fine, but recently her wandering has gotten worse. I find her in the kitchen trying to cook, creating dangerous situations like putting tinfoil in the microwave. And sometimes at night she gets up and tries to leave the house for "work". It has been getting more difficult to keep track of her. When I told my friend about this she mentioned something about a monitoring system with video cameras. This sounds strange to me. Does anybody use video cameras to monitor their loved one with Alzheimer's?

—Hall Monitor

Thank you for your question HM. Some family members do put up security cameras or motion detectors to monitor loved ones when they are still living alone or when wandering becomes an issue. It seems to work best when family is living very close by or is trying to get additional information about their loved one's activity. And it often helps the family better care for that individual. However, it certainly poses a question of privacy and I would recommend that there be a legal representative (like a Power of Attorney or guardian) involved in this type of decision. I would also recommend a consultation with someone at the Alzheimer's Resource of Alaska to provide more in-depth information.

Facts and Figures

In 2010 Alaskans provided **\$213 MILLION** in unpaid care for by caring for a family member or friend with dementia.

Last year, Alzheimer's Resource of Alaska facilitated **153 SUPPORT GROUPS** across the state.

In 2010 almost 31,000 Alaskans provided over **25 MILLION HOURS** of unpaid care to an individual living with Alzheimer's disease or related dementia.

Facts and Figures

Alzheimer's Resource of Alaska served **102 COMMUNITIES** last year.

Alzheimer's disease usually begins after age 60 and **RISK INCREASES WITH AGE**. Younger people in their 30s, 40s and 50s may get Alzheimer's disease, but it is rare.

While there is no cure for Alzheimer's disease, there is **QUALITY CARE AVAILABLE**.

Mental Fitness

KEEPING OUR BRAINS HEALTHY and active is good advice at any age. Like any other part of our body the mind needs to be exercised. However, rarely do we do an activity with the deliberate intention of "working out" our minds. Some may think it is unnecessary since cognitively stimulating activities can be as simple as reading, doing crossword puzzles or learning a new word. But as we age, it becomes more and more important to seek out these activities.

When we are young, we go to school every day. We are constantly learning, reading and problem solving in various areas of study. But later in life we tend to lose some of these activities. This can be simply because we don't have the time to dedicate towards them, or maybe our job makes us utilize one area of the brain more than others. But like any other muscle, if an area of the brain is neglected it becomes weak.

Participating in structured mental fitness programs, no matter what age, can help challenge and exercise different areas of the brain in ways we may not do on our own. In these programs, various activities are created to stimulate creative, logical and problem solving functions in an entertaining way.

Though it is still unknown what causes one person to develop Alzheimer's and not another, studies have

shown lower rates of Alzheimer's disease in people who maintain an overall healthy lifestyle. That includes physical exercise, maintaining a healthy diet, reducing stress, not smoking and engaging in social and cognitively stimulating activities. So let's get started by doing a few fun "workouts."

STIMULATING CREATIVITY:

Figure out what these re-written proverbs are:

The previously arriving feathered, winged biped captures the invertebrate crawler.

It's vastly preferable to remain unscathed than to be forced into repentance.

If you refrain from interrogating me, I'll articulate to you no prevarications.

When the terrain becomes arduous, the resolute becomes vigorous.

Heedful prudence is the preferred component of intrepidly.

Now re-write your own variations.

This activity is courtesy of Robert Winningham Ph.D., Geriatric Wellness Center at Northwest Rehabilitation Associates.

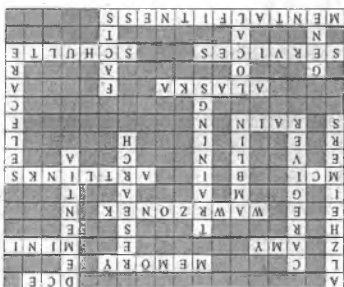
ACROSS

2. Prgm. for direct care workers (abr.)
4. _____ Screenings
6. Volunteer Extraordinary
7. Grant for individuals with Alzheimer's or related dementia
9. Education Director of Alzheimer's Resource of Alaska
11. Term for early memory loss abr.
12. Self-expression program for a memory impaired person
14. Elsie collects this
15. Has the fastest growing aging population in the nation
19. Care Coordination, respite, chore
20. UAF research lab
21. Stimulates the mind

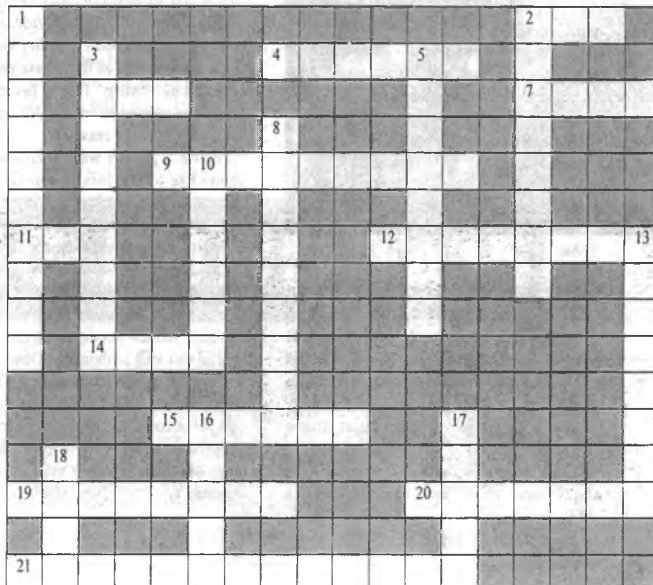
DOWN

1. The sixth leading cause of death in the country
2. Term to describe a number of symptoms affecting cognitive function
3. Jim Clark
5. Important to someday finding a cure
8. Savvy Professional, Savvy Caregiver, DCE
10. Annual walk to benefit Alzheimer's Resource of Alaska
13. Important for caregivers
16. 1750 Abbott Rd. is Anchorage's _____ Alzheimer's Resource of Alaska Office
17. One in eight people over the age of 65 and one in two over 85 will develop Alzheimer's AND 6000 Alaskan's currently live with ADRD
18. APP, PSEN 1 or PSEN 2

Puzzle Answers



The early bird catches the worm.
 Better safe than sorry.
 Ask me no questions, I'll tell you no lies.
 When the going gets tough, the tough get going.
 Discretion is the better part of valor.



It's more than a helping hand...

LOIS REPNOW AND HER HUSBAND KELLY have six children, ages 7 and under. It has been over a year since Kelly's father TeRoy Repnow, who was diagnosed with Alzheimer's disease, came to live with them. The Repnows fit the "sandwich generation" description where they are caring for an elderly parent while still raising their own children. Due to several circumstances in the family, the choice became that either TeRoy came to live with the family or he went to an Alzheimer's care facility. At the time, Lois was pregnant with their sixth child. So the family was growing by two. In February, TeRoy's granddaughter was born and this was a time which Lois remembers vividly, "I will never forget the tenderness with which TeRoy held his newest granddaughter."

The Repnows have been happy to have this time with TeRoy. "I have been very blessed to watch my children get to interact with their grandpa and love on him. Children are without guile and lavish love freely no matter one's physical or mental condition." Says Lois.

But caring for grandpa TeRoy has not always been easy on the family. His Alzheimer's is fairly advanced and he has become almost like another "chicky in the nest" according to Lois. However, he is an adult, and that carries its own challenges. TeRoy's needs have grown even in the short time he has been staying with the Repnows. The family's laundry load increased when TeRoy moved in. There were a few more spills around the house and his bedding needed to be washed frequently. This put a strain on the family's septic system and their basement in danger of flooding.

When the family contacted the Palmer Senior Center to find out what resources were available they learned of the Mini-Grant program administered by the Alzheimer's Resource of Alaska and funded by the Alaska Mental Health Trust Authority. They applied for the grant and were awarded a small amount to purchase resources that would help the family care for TeRoy.

With these funds the family purchased vitamins, a monitoring system, towels and a large capacity, resource efficient washer and dryer. The monitoring system allows Lois to go up and down the stairs to do all her daily tasks without having to worry about taking TeRoy with her to each room of the house. And the washer and dryer may have helped the most, "I can easily load 15-20 towels in one load, wash Dad's sheets and bedding in one load... I can do all of my laundry without having to worry about overtaxing the septic system and flooding our home!"

Lois and her family are extremely grateful for the mini-grant. They can now spend less time doing chores and spend more time enjoying grandpa TeRoy while he is in their home.

TeRoy has since moved to North Dakota to be closer to his wife in an assisted living facility where he can see her every day. It has been a joyful reunion for a couple that has been married 59 years. And should the need arise, he is welcome back in the Repnow home at any time.

Mini-Grants are awarded by the Alzheimer's Resource of Alaska and funded by the Alaska Mental Health Trust Authority. Applicants can apply for up to \$2500 for items or services that improve the quality of life for a loved one diagnosed with Alzheimer's or related dementia.

Upcoming events

November is Alzheimer's Awareness Month www.AlzAlaska.org

Research Forum: Dr. Joshua Gatson regarding research in traumatic brain injuries and the link to Alzheimer's Disease.

October 31st from 6-8 pm at Providence Hospital East/West Auditorium, Anchorage

November 1st from 6-8 pm at Public Library, Fairbanks

November 2nd from 6-8 pm at the University Campus, Soldotna

November 3rd from 6-8pm at Centennial Hall, Juneau

When does Forgetting Become a Disease?

November 3rd from 10-12 noon at the Anchorage Senior Activity Center

WineStyles wine tasting & silent auction

November 5th from 7-10 pm at the Alaska Native Heritage Center

ABC's of Caregiving: What about the Kids? Alzheimer's through the eyes of a child

November 7th from 10-12 noon or 5:30-7 at Alzheimer's Resource of Alaska, Anchorage office

ABC's of Caregiving: When does Forgetting Become a Disease?

November 8th from 6-7:30 Alzheimer's Resource of Alaska, Palmer office

Momentum in Science: A film exploring scientific efforts to uncover the causes of Alzheimer's

November 10th from 10-12 noon at the Anchorage Senior Activity Center

National Memory Screening Day

November 15th Call your local office for events and appointments

ABC's of Caregiving:

Holidays and traveling with those who have dementia

November 16th from 10-12 noon or 5:30-7 at Alzheimer's Resource of Alaska, Anchorage office

Being a Friend: Staying Connected with Individuals with Alzheimer's Disease or Related Dementia

November 17th 10-12 noon at the Anchorage Senior Activity Center

Open House: Join classes, listen to presentations, meet staff and learn about the support and services of Alzheimer's Resource of Alaska.

November 18th from 1-5 at Alzheimer's Resource of Alaska's offices in Anchorage and Palmer

Alzheimer's Disease:

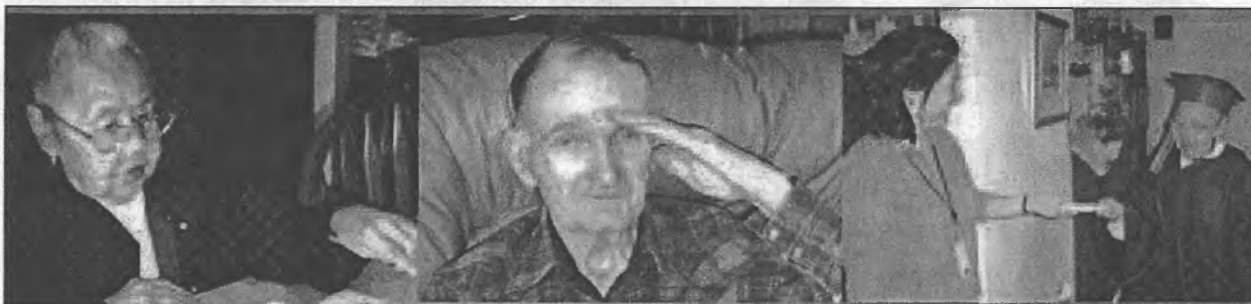
Unraveling the Mystery

November 28th from 10-12 noon or 5:30-7 at Alzheimer's Resource of Alaska Anchorage office

Art Links:

Every Friday in Anchorage from 11-12 noon

Every Friday in Palmer from 1-2 p.m.



ASSISTED LIVING ASSOCIATION of ALASKA

VISIT OUR WEBSITE FOR MORE INFORMATION: WWW.ALAA-ALASKA.ORG
OR EMAIL US AT ALAA-ALASKA.ORG



One Woman Making a Difference



OVER THE PAST FOUR YEARS Amy DeWitt has dedicated an extraordinary amount of time and effort to Alzheimer's Resource of Alaska. She has volunteered for numerous events as well as raised over \$16,000 fundraising for Amblin' for Alzheimer's. Unbelievably, she has done all of this while raising six children and holding a full time job.

Amy got involved with Alzheimer's Resource of Alaska when she started serving Jackie Brunton and her mother Dorothy at the Bradley House seven years ago. The two would come in to eat about three to four times a week and Amy would go out of her way to make sure Dorothy was comfortable. Dorothy had Alzheimer's disease, and Jackie was caring for her at the time.

"It was about the only place I could take her. It is small, quaint and not overwhelming" Jackie explains. "And Amy took such good care of my mom."

Amy always had hugs and kisses for Dorothy when they came in. And when Dorothy stopped eating most foods, the kitchen started making her favorite dish, chicken fingers (which can now be found on the Bradley House menu). Amy even had the chicken fingers cut up so that Jackie wouldn't have to do it at the table and could enjoy a meal with her mother.

In 2008 Dorothy passed away, and around the same time Amy found out her grandfather Fredolin was diagnosed with Alzheimer's as well. The following year Amy decided to participate in Alzheimer's Resource of Alaska's fundraising walk, Amblin' for Alzheimer's. That first year, she and her youngest son Haden raised \$1,621 for the organization.

This amount won her the top fundraising prize for all of Alaska in 2009. Amy was in shock when she learned she won. She wasn't even trying to compete with anyone. She found out when Jackie, who was then Board President of Alzheimer's Resource of Alaska, surprised Amy at work and presented her with two round-trip tickets courtesy of Alaska Airlines to anywhere she wanted to go. Amy knew right away it was Hawaii.

To top it off, when another set of her regulars at Bradley House found out she won the tickets they gave her their timeshare in Hawaii to use. Amy still can't believe they did that for her, but Jackie doesn't seem surprised.

"You know it really says a lot about Amy. She's so genuine, I don't know how else to describe her."

In 2010 and 2011 Amy kept up the momentum by raising more money for Amblin' than any individual in the state. However, since that first trip she took to

Hawaii, all of the prizes she has won over the years she has given away.

When she won both of the following years she gave the airline tickets to her parents, and sent them off to Hawaii.

"They absolutely deserved it," she said. "They have never taken a vacation."

Over the years, ensuring that individuals with Alzheimer's have the services they need has become a cause that is deeply important to Amy. When she visited her grandfather on his birthday for the last time in 2010 Amy gained a clearer understanding of what takes place with the disease how it affects everyone who comes in contact with it.

She watched as family members expectations were let down as they visited and interacted with Fredolin. They wanted him to remember who they were and would say things like, "Hey grandpa, it's me! Don't you remember me?" And though their intentions were good, this would leave both people feeling disappointed. Her grandfather was frustrated because he had no idea who was talking to him but felt like he should, and the other person left the exchange sad and feeling forgotten.

It wasn't until seeing her Aunt Carol talk to Fredolin that Amy understood how simple changes of speech can alter an interaction completely. She watched as her grandfather lit-up when her aunt went to him and said "Hey, it's your birthday! Happy birthday!" she smiled, gave him a kiss and nothing more.

"Aunt Carol didn't need anything from him" Amy says. "She was just there to celebrate the day with him."

It was at that moment that Amy says it became apparent, "it is not about what we need from them, it is about what we can give to them."

Everyday she continues to give in a number of ways whether it is at the Bradley House or the Alzheimer's Resource of Alaska. For 2012 Amy has a slightly different plan from what she has done in the past. When Amblin' comes around next year, Amy may do some fundraising but will not be trying to break any more records.

"It's time for someone else" she says.

Not to say that she will be slowing down. Amy will just be committing her time to the organization in other ways. This year she is organizing donations and coming up with ideas for the silent auction benefit in November hosted by WineStyles. And she is already planning to donate her time as a server for Date Night in February.

"She just gives back" Jackie says, "and she does so much for so many... I couldn't love her anymore if she were [my] blood."

But Amy doesn't do it for the praise. Her dedication to Alzheimer's Resource of Alaska and the work they do, can be seen in her teary eyes as she says, "I just hope somebody was able to treat my grandfather like we do here."

Facts and Figures

ONE IN EIGHT people over the age of 65 will develop Alzheimer's disease, and nearly one in two over the age of 85.

Alaska has the **FASTEST GROWING** aging populations in the nation.

Approximately **6,000 ALASKANS** are currently living with Alzheimer's disease and related dementia and as many as 5.4 million Americans nationwide.

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We Offer You Peace Of Mind While Providing Your Loved Ones With...

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- ✓ Dignity
- ✓ Security in Daily Living



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