

## The End of Alzheimer's Starts Here

### Walk to End Alzheimer's™ 2011

**T**his fall, join the more than 9,800 people in Minnesota and North Dakota who will raise awareness and funds by walking to end Alzheimer's. Since 1989, the Alzheimer's Association has mobilized millions of Americans in the Alzheimer's Association Memory Walk®; now, the Association continues to lead the way with the Walk to End Alzheimer's. The Minnesota-North Dakota Chapter will raise money at 16 Walks in September and October to provide help and hope to those impacted by dementia through education and support services, state and federal advocacy and research into treatment, prevention and a cure.

Wherever you live, there's a Walk near you. New Walks are taking place in Warroad and Willmar, MN, and other walks take place throughout the two states. There is no registration fee or fundraising minimum for the Walk to End Alzheimer's, but each walker is encouraged to set a personal goal to raise \$200. Plus, every walker who raises \$100 will receive the official 2011 Walk T-shirt! Online registration is encouraged and tools, promotional help and fundraising ideas are available online to help all participants meet their goals.

This movement to end Alzheimer's also needs advocates. When you register online, select the option to become an advocate and speak up for the needs and rights of people with Alzheimer's disease and their families.

Together, we can end a disease that is the nation's sixth-leading cause of death; and together we can reclaim our future. Start or join a team at [alz.org/walk](http://alz.org/walk).

### We Need Volunteers

**Walk to End Alzheimer's** would not be possible without fantastic volunteers. Volunteers are needed to help with a variety of areas including event setup, registration, walker patrol, roaming advocates, cheerers and event breakdown. If you are interested in volunteering, email [walkmnnd@alzmndak.org](mailto:walkmnnd@alzmndak.org) to learn more.



### 2011 Walk to End Alzheimer's

Join us today by signing up for a 2011 Walk near you:

- Bismarck, ND, Sept 24
- Brainerd, MN, Sept 24
- Dickinson, ND, Sept 10
- Duluth, MN, Oct 1
- Fargo, ND, Sept 17
- Grand Forks, ND, Sept 10
- Mankato, MN, Tue, Sept 17
- Minot, ND, Sept 17
- Red Wing, MN, Oct 8
- Rochester, MN, Sept 10
- St. Cloud, MN, Sept 24
- Twin Cities, MN, Sept 24
- **Warroad, MN, Sept 17**
- Williston, ND, Oct 1
- **Willmar, MN, Oct 1**
- Winona, MN, Sept 24

*All dates are Saturday events. **Bold dates** are new Walks.*

### Steps to Join

1. **SIGN UP** for a Walk at [www.alz.org/walk](http://www.alz.org/walk) and check the "advocate" bubble during registration process.
2. **SET UP** your Personal Page.
3. **START** a Team and Recruit Members.
4. **FUNDRAISE** Online.
5. **USE** social networking to spread the word.



## Younger-onset Alzheimer's disease



Terry R. Barclay

By Terry R. Barclay,  
PhD

One of the biggest myths about Alzheimer's disease is that it develops only late in life, in a person's 70s or 80s. When most people think of Alzheimer's disease, they think of very elderly, very disabled people living in nursing homes. Yet while most people with the disease are older, Alzheimer's can strike some people as young as their 30s.

Younger-onset Alzheimer's disease, sometimes called early-onset Alzheimer's disease, is a form of dementia diagnosed before the age of 65. Individuals with younger-onset can be in any stage of dementia when they receive a diagnosis, with symptoms from mild to severe, but they are under 65 when the condition first emerges. The National Institute on Aging estimates that 5 to 10 percent of the 5.4 million Americans living with Alzheimer's disease are under the age of 65. The Alzheimer's Association estimates the number in Minnesota and North Dakota to be around 4,700.

### Symptoms

Although expressed at an earlier age, the symptoms of younger-onset Alzheimer's disease are very similar to those seen in traditional Alzheimer's and can include:

- Loss of recent memories severe enough to disrupt daily life.
- Trouble organizing and expressing thoughts.
- Difficulty finding words or names of objects, places or people.
- Problems concentrating or multi-tasking.
- Diminished ability to interpret symbols or understand directions.
- Difficulty planning or solving problems.
- Becoming disoriented or lost in familiar places.
- Withdrawal from social activities.
- Poor motivation, apathy, depression, anxiety, irritability or other mood changes.

Not all people with younger-onset Alzheimer's experience symptoms in the same order or progress through the illness at the same speed. Scientists are still learning about individual factors that contribute to how symptoms are expressed and what can be done to slow their progression. Researchers have found several genes linked to the younger-onset form of the disease; many of those affected have a relative who also developed the condition at a younger age.

### Diagnosis

There are many reasons why people are encouraged to talk with their doctors about memory loss and pursue an appropriate diagnosis as early as possible. An early diagnosis means:

- Medication treatments may be more effective.
- More time to plan for the future.
- Needs can be anticipated and crises minimized.
- Access to valuable support services.
- Faster approval of Social Security disability benefits.
- Opportunities to enroll in clinical trials for new, investigational medications.
- Home life can be optimized to promote independence.
- Family and friends can learn how to provide support when it is needed.

Even with proper medical attention, obtaining an accurate diagnosis of younger-onset Alzheimer's can be a long and frustrating process. Alzheimer's is not routinely expected in younger individuals. When a person younger than 65 goes to the doctor with memory loss and other hallmark symptoms of the disease, their physician may not consider Alzheimer's as a possibility. In many cases, early symptoms are attributed instead to stress, menopause, "normal aging" or mood problems.

### Unique challenges

Those with younger-onset Alzheimer's disease face distinct challenges. Many are still working when their symptoms emerge. Due to the nature of the condition, changes in their job performance or behavior may not be understood or addressed. Those who are fired or who leave their jobs before obtaining a diagnosis may never be offered employer assistance that would otherwise be provided to an individual with a recognized disability. Job loss can also mean loss of insurance coverage and tremendous financial burdens. A spouse or partner may need to increase work hours to help support the household. In addition, since most services for people with dementia are designed for older individuals, those with younger-onset often do not feel comfortable in traditional community programs.

### Treatment

The medications currently available to treat younger-onset Alzheimer's are the same as those used in the traditional form of the disorder. While none of the medications stop or reverse the underlying progression of the illness, they do offer benefits to many people, particularly in the first 12 to 18 months of treatment when the disease is identified early. Other medications, such as those to improve mood and sleep, also may be used.

## Comfort Zone Brings Families Peace of Mind

**A**lzheimer's Association Comfort Zone Check-In™, powered by Omnilink, is a simple and affordable solution that offers greater freedom and independence for people with Alzheimer's and those who care about them.



Comfort Zone Check-In™ is a self-service web-based location management service. Families can monitor a person with Alzheimer's using on-demand “Find Me” and “Follow Me” sessions, while receiving daily scheduled location alerts.

Comfort Zone Check-In™ is the only system designed specifically with Alzheimer's in mind. It uses the most advanced tracking application and devices to track the location of a person with Alzheimer's.

Among the benefits ComfortZone Check-In™ provides:

- **Easy to Use** – As simple as turning on a computer or charging a phone. No installation of software. Manage account on the web at anytime.
- **Flexibility & Choice** – Comfort Zone Check-In™ can be paired with a variety of devices and plans. Choose the solution that fits you best.
- **Independence & Security** – Allows multiple family members, no matter where they live, to check on a person with Alzheimer's.
- **Access to Resources** – Access to all the resources of the Alzheimer's Association, including a free 24/7 Helpline that provides confidential counseling, referrals, safety and disease education, and local support.

### Need Comprehensive Service?

Alzheimer's Association Comfort Zone® , powered by Omnilink, has been available since 2009 and is a comprehensive, web-based location management service. Families can remotely monitor a person with Alzheimer's by receiving customized alerts through the day and night when a person has travelled beyond a preset zone. It includes enrollment in the MedicAlert + Alzheimer's Association Safe Return program, a 24-hour response service for wandering and medical emergencies.

## YOUNGER-ONSET from page 2

In addition to medication treatment, creating more structure and routine in daily activities can help people stay focused. Other recommendations include reducing alcohol use, maintaining a healthy diet, seeing the doctor regularly, increasing physical activity and exercise,

staying socially engaged, and finding new ways to keep mentally stimulated.

*Dr. Barclay is a neuropsychologist who specializes in aging and dementia. He sees patients at the HealthPartners Center for Dementia and Alzheimer's Care and maintains a private practice in Edina.*

## Memory Meetup & Mentor

Welcome to Memory Meetup & Mentor! We are a group that likes to do something, learn something, share something, change something. Members describe our group as The Trailblazers.

This program is designed to build a safe and comfortable social meeting space both virtually and in-person for individuals with MCI or early Alzheimer's disease and their care partners. In-person social meetings, posted on the website, occur once a month at a Twin Cities location determined by the group.

Mentors with MCI and early Alzheimer's disease connect with newly diagnosed individuals who have contacted the Alzheimer's Association Helpline or who have participated in Association-affiliated early stage programs. Mentors call and connect with the individual and invite them to join the Memory Meetup online and in-person social gatherings.

We look forward to meeting up with you online and in-person.

*Sara Tucker and the Meetup Trailblazers*  
[www.meetup.com/Memory-Mentor](http://www.meetup.com/Memory-Mentor)

For more information, please contact Sara Tucker, Early Stage Manager, at [sara.tucker@alz.org](mailto:sara.tucker@alz.org) or 952-857-0553.

## Activities for Persons with Dementia – a Win-Win



Monica Heltemes

By Monica Heltemes, OTR/L

**W**hat does “doing things” mean to you? Reading a book, knitting a scarf, playing a round of golf? What about for persons with dementia, who experience memory loss, loss of planning and organization skills and decreased initiative to do things? For them, “not

doing” activities may result in pacing, sleeping, boredom or restlessness. This can lead to excess disability or disability beyond what can be attributed to the disease itself. This can lead to a faster rate of decline.

According to a survey administered by the National Alliance for Caregiving, caregivers are looking for ideas for easy activities they can do with their loved one.<sup>1</sup> Keeping persons with dementia active not only offers caregiver support but also important cognitive stimulation and engagement for the user. But often, caregivers are unsure how to go about helping with this process.

Here are three key tips on how caregivers can help keep persons with dementia active. Remember the “3 R’s” of education – Reading, ‘Riting and ‘Rithmetic? Let’s replace those with these three R’s – Routine, Reduce and Reassurance.

### Routine

Persons with dementia do best with routine. To help bring some order to a confusing world of forgetfulness, the person needs the same activities done in a typical order and timeline each day.

Think of incorporating different types of activities into the typical day. For example, something social, such as eating breakfast together and something physical, such as taking a walk. Also, try to incorporate activities based on the person’s past interests. Last, choosing activities that you, as a caregiver, also like to do will make it more enjoyable for both of you.

### Reduce

Persons with dementia have short-circuits in the way their brain works. They need things to be reduced, so that they can work their way around short-circuits. Examples include:

- Reduction in the number of steps of the task (e.g., making pudding instead of cake)
- Reduction in the directions given for the task (e.g., yes/no questions instead of open-ended)
- Reduction in the level of abstractness of the task (e.g., task supplies set out by the caregiver)

The level of reductions that need to be made will vary, depending the extent of the deficits or short-circuits the person has.

### Reassurance

The person with dementia may at times be reluctant to participate when you ask them. This may be due to fear of failure. A more reassuring and successful way to ask him to do something is to ask for his help.

Offer reassurance throughout the activity and after. “You are doing great! Thanks for your help!” This gives the person pride in that moment, a feeling that can last long after the activity.

According to research, the benefits for the person staying active include minimizing the rate of cognitive decline, improved sense of self worth and improved sleep<sup>2,3</sup>. The benefits for caregivers are increased satisfaction with caregiving and a reduced amount of challenging behaviors to address<sup>4,5</sup>. Keeping the person with memory loss active is a win-win for both partners of the team. To learn more about products to keep persons with dementia active, call the 24/7 Information Helpline at 1-800-272-3900.

*Monica Heltemes is a practicing occupational therapist and Owner of MindStart™. MindStart designs and produces activity products specifically for persons with memory loss.*

### REFERENCES

<sup>1</sup> Caregiving in the U.S. Published April 2004 by National Alliance for Caregiving and AARP.

<sup>2</sup> Brooker, D. J., & Woolley, R. J. (2007). Enriching opportunities for people living with dementia: The development of a blueprint for a sustainable activity-based model. *Aging & Mental Health*, 11, 371 – 383.

<sup>3</sup> Smith, M, Kolanowski, A, Buettner, L, Buckwalter, K. Beyond Bingo: Meaningful Activities for Persons with Dementia in Nursing Homes. *Annals of Long Term Care*. 2009; 17:7, p. 22-30.

<sup>4</sup> Gitlin LN, Winter L, Vause Earland T, Herge EA, Chernet NL, Piersol CV, Burke JP. The Tailored Activity Program to Reduce Behavioral Symptoms in Individuals With Dementia: Feasibility, Acceptability, and Replication Potential. *The Gerontologist*. 2009; 49: 429.

<sup>5</sup> Hasselkus, B., & Murray. (2007). Everyday Occupation, Well-Being, and Identity: The Experience of Caregivers in Families With Dementia. *The American Journal of Occupational Therapy*, 61(1), 9.

## Golf Tournaments Benefit Alzheimer's Association

The Alzheimer's Association is teeing up for a great summer of golf! This summer, the Association has been chosen as the beneficiary of three outstanding golf tournaments.

### Driving to Donate Golf Tournament

On Friday, August 19, 2011, Allianz will host its annual "Driving to Donate" golf tournament at Bunker Hills Golf Course in Coon Rapids, MN. The tournament begins at 8 a.m. with more than 215 golfers expected.

"One great thing about Allianz Life Insurance Company of North America is the way our employees and company vendors come together to make a difference. We have set a goal of raising \$70,000 for the Association to support those living with this devastating and heartbreaking disease," said Allianz Community Relations Specialist Laura Juergens.

Limited company sponsorships and player registrations are available by contacting Laura Juergens at [laura.juergens@allianzlife.com](mailto:laura.juergens@allianzlife.com).

### Golf Scramble for Alzheimer's

Univita is set to host its fourth-annual Golf Scramble for Alzheimer's Disease on Friday, August 19, 2011, at Braemer Golf Course in Edina, MN. A 1 p.m. shotgun start will kick off the event. The 18-hole entry fee is \$125 and includes a boxed lunch, cart, green fees, Univita logo polo shirt, dinner buffet, a drink ticket and chances to win door prizes.

"The golf tournament was created as a charitable and fun



way for our employees to raise money for the Association's Walk. This year's event is sure to be the most successful yet as we are expecting over 150 players and 60 volunteers," said Lynne Ferrell of Univita.

For information or to register, contact Lynne Ferrell at 651-501-4304 or [lferrell@univitahealth.com](mailto:lferrell@univitahealth.com).

Both Allianz and Univita are Alzheimer's Association Minnesota-

North Dakota 2011 Angel Sponsors and, as such, they graciously raise and/or donate more than \$25,000 annually to the Alzheimer's Association.

### Alzheimer's Golf Classic

On Monday, September 26, 2011, the Brouillette Group will host its first Alzheimer's Golf Classic at the Southview Country Club in West St. Paul. Celebrity Chair Doug Woog will be on hand for a 1 p.m. shotgun start and the \$125 fee includes lunch, dinner, golf and cart rental. For more information, contact Chad Fuenffinger at The Brouillette Group at 763-746-2734 or [chadf@BGinsure.com](mailto:chadf@BGinsure.com).

The Alzheimer's Association is grateful to all those across Minnesota and North Dakota who host events to benefit the Association and the people we serve. To see a list of upcoming benefit events, visit [www.alz.org/mnnd](http://www.alz.org/mnnd). If you have an idea for an event or would like more information about hosting one, contact Ashley Snell, Associate Director, Constituent Events, at [ashley.snell@alz.org](mailto:ashley.snell@alz.org) or 952-857-0532.

## PLEASE DON'T TOSS THIS NEWSLETTER!

We encourage you to "recycle" your newsletter. Share it with a friend, doctor's office, house of worship or club. Contact Carla Zbacnik at [carla.zbacnik@alz.org](mailto:carla.zbacnik@alz.org) or (952) 857-0526 if you'd like to be removed from our mailing list or would like to receive this newsletter via e-mail.

This newsletter is published twice each year by the Alzheimer's Association Minnesota-North Dakota, a nonprofit, tax-exempt corporation.

Your newsletter comments and ideas are always welcome.

Please send them to:

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or by e-mail to [carla.zbacnik@alz.org](mailto:carla.zbacnik@alz.org).

## SAVE THE DATE!

The 2012 Meeting of the Minds Dementia Conference will be held Saturday, March 17, at the RiverCentre in St. Paul. Contact Jennifer Schroeder, Corporate and Donor Relations Manager, to secure your spot at 952-857-0536 or [jennifer.schroeder@alz.org](mailto:jennifer.schroeder@alz.org).



## 2011 Conference Sponsors

The Alzheimer's Association is grateful for the generous support of *A Meeting of the Minds Dementia Conference 2011*.

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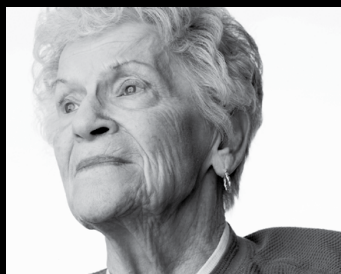
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Synergy HomeCare  
The Alton Memory Care and The Wellington Assisted Living  
The Wellstead of Rogers Campus: Memory Care & Senior Living

## GET THE FACTS Free Education Series

*What you need to know about memory and Alzheimer's disease*



Are you or is someone you know living with Alzheimer's disease or a related dementia? This FREE educational series tackles the most common challenges faced by people with dementia and their care partners.

Join us every month! The next series starts in September. For more information, contact Marsha Berry at [marsha.berry@alz.org](mailto:marsha.berry@alz.org) or 952-857-0541 or visit [www.alz.org/mnnd](http://www.alz.org/mnnd).

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## Remembering Our Stars Gala Raises More Than \$430,000



(l-r) Chris Nowinski, Executive Director Mary Birchard, Emily and Ryan Oberlander.

**O**n April 16, the 19th Annual Remembering Our Stars—Lighting the Way Gala brought together more than 880 guests and volunteers to honor those with Alzheimer's and related dementias and successfully raised more than \$430,000 to support the programs and services of the Alzheimer's Association.

Guests enjoyed a festive evening including a special performance by a volunteer choir conducted by Kathy Saltzman Romey and accompanied by Bryce Hayes, as well as a research update by Dr. Ron Petersen, director of the Mayo Alzheimer's Disease Research Center, and a keynote presentation by Chris Nowinski, who spoke on *Solving the Sports Concussion Crisis*.

Special thanks go to gala chairs Emily and Ryan Oberlander, as well as to the dedicated volunteer gala committee, sponsors, event donors and volunteers. Next year's gala will be held on May 19, 2012, at The Depot Renaissance Minneapolis Hotel. For more information, please contact Stephanie Dix at 952- 857-0545 or [stephanie.dix@alz.org](mailto:stephanie.dix@alz.org).

**Lighting *the* Way**  
**Remembering Our Stars Gala**

## Thank You 2011 Gala Sponsors

The Alzheimer's Association is grateful for the generous support of this year's gala sponsors.

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### Community Health Charities

The Alzheimer's Association is a member of Community Health Charities, an alliance of leading nonprofit health research and service organizations, whose mission is to improve

lives affected by chronic illness by investing in health research, services and education. [www.healthcharitiesmn.org](http://www.healthcharitiesmn.org).



### Meets Accountability Standards

The Alzheimer's Association Minnesota-North Dakota has undergone a review by the Charities Review Council, which evaluated our public disclosure, financial activities, governance and fundraising. This review determined that the Association meets the Council's accountability standards – demonstrating our integrity and transparency to the people who support us. To see the Council's full report, visit [www.smartgivers.org](http://www.smartgivers.org), click on "For Donors," then click on "Charity Search" and search for "Alzheimer."



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