The words “Alzheimer’s disease” and “dementia” can trigger negative images and emotions that stigmatize those affected. Even as public awareness about Alzheimer’s disease and related disorders increases, the stigma persists in our society and in our own minds, consciously or not. The stigma is perpetuated by stereotypes and myths about dementia portrayed in the media; the misperception that a diagnosis means the immediate onset of the end stages of dementia; and the belief that since there is not yet a cure then there is nothing that can be done except endure.

Thankfully, recent scientific progress has dramatically increased our understanding of Alzheimer’s disease and related disorders and has led to improved diagnosis and treatment. The ability to accurately diagnose progressive memory loss and cognitive impairments has improved to about a 95% accuracy rate with a good diagnostic workup. There is hope of new, more effective medications and medical treatments on the horizon.

Equally as important, experts in the field, like those at the Alzheimer’s Association, know what can be done to help individuals and families live with Alzheimer’s disease with as much quality of life as is possible. The saying “information is power” has never been more true as people seek hope and help that will sustain them through the journey with progressive memory loss.

Unfortunately, stigma contributes to the tendency toward “denial.” Denial is a natural response to any diagnosis of a progressive illness; too much denial prevents us from getting the information we need. Fear, guilt, doubt, anger, grief — are some reactions that any individual or family member would have to a diagnosis of dementia. Who wouldn’t turn to a bit of denial to cope with these feelings? The message is not that it is wrong to have these feelings; any one of these emotions is a natural response to a very difficult set of circumstances. What is important is how we choose to handle the feelings. For a caregiver or newly diagnosed person, a bit of denial can be a healthy way to cope, but it is important to recognize that there really is a helpful and hopeful world of information out there if we can reach out and find it. Both the caregiver and the person with dementia will benefit from this knowledge.

For families living with Alzheimer’s disease, it takes a great deal of courage to overcome stigma and come to terms with the diagnosis in order to feel comfortable enough to share the diagnosis with others and to come forward to ask for help. Families living with Alzheimer’s disease should be patient, as acceptance takes time. In Betsy Peterson’s book Voices of Alzheimer’s, a care-partner explains, “It took us a good six months to tell my husband’s daughter. We just had to come to the realization ourselves before we could talk with family members. We had to accept it for ourselves before we could explain it to others.”

continued on page 10
I recently returned from a meeting of our national Delegate Assembly in Chicago where volunteer leaders from Alzheimer’s Association chapters across our nation voiced their commitment to combat Alzheimer’s, and approved a new nationwide strategic plan – a plan that will guide both our Chapter and our Association throughout the United States. I realize that this is not the heady stuff of earth shattering media headlines, but there is an ambitious, almost brazen tone to this plan. The reason for aggressiveness: we are running out of time. We need to wake up the American people and galvanize them to join our cause. We need to engage both our federal elected leaders as well as officials in state houses around the country, so that we can make the investments today that will avoid the onslaught as boomers experience Alzheimer’s tomorrow.

The plan calls for increasing our efforts to raise public awareness so that more Americans know about Alzheimer’s disease and the ways in which the Alzheimer’s Association is making a difference. We will increase our efforts to engage people in the early stages of Alzheimer’s to become leaders and advocates for our cause. We will ramp up our efforts to improve access to our programs and services and make sure we are effectively reaching underserved communities. We will expedite our work to recruit advocates and engage champions so that the critical issues of concern to those living with Alzheimer’s become a priority for policy makers. And, we will accelerate our progress in Alzheimer’s research, so that critical medical interventions come to market as soon as possible.

None of this will be possible without the active involvement of thousands of volunteers. Whether as advocates, support group leaders, Helpline volunteers, educational presenters, Memory Walkers and other volunteer fundraisers, we cannot possibly achieve our goals without your help. We look forward to working together with you.

—James Wessler, President and CEO

Our mission is to eliminate Alzheimer’s disease through the advancement of research, to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health.

Our vision is a world without Alzheimer’s.
helpline corner

By Lindsay Brennan, Manager, Helpline Services

Q: My husband is 82 years old and has had Alzheimer’s for about 5 years. Lately he has not been sleeping through the night like he used to. He often wakes up in the middle of the night and is confused and anxious. What is causing this and what can I do about it?

A: It is very common for people with Alzheimer’s disease to experience changes in sleep patterns. Tell your husband’s physician about the changes you are observing. We do not know exactly what causes all the sleep changes associated with Alzheimer’s, but it is important to consider common sleep-changing conditions like nightmares, depression or sleep apnea. Also, consider his daily activities. A daily structured, active routine that includes regular mealtimes, exercise, exposure to sunlight and meaningful tasks and activities will contribute to a quality night’s sleep. It might be challenging for you to organize his days, so consider using community-based services, such as homecare companions and Adult Day Health Programs. Also, try to have him wake and retire at about the same time each day. Be sure that the bedroom is a comfortable temperature and limit his fluid intake in the evening. If he currently takes a Cholinesterase Inhibitor (Aricept, Exelon or Razadyne) at bedtime, talk with his doctor about switching to morning, as these medications are known to contribute to sleep disturbances. If he is continuing to have sleep problems, consider discussing sleep aid medications with his physician.

Be a Champion…
Join us on the MOVE!

Since 1989, Memory Walk has raised more than $225 million to help those battling Alzheimer's disease. The Alzheimer’s Association, the leading voluntary health organization in Alzheimer research, care and support, is dedicated to finding prevention methods, treatments and an eventual cure for Alzheimer’s and providing support for all those affected by the disease.

This year, New Hampshire will host four walk locations throughout the state on Saturday, September 20th: Capital Area Walk at the State House Lawn in Concord; Monadnock Region Walk at Keene State College in Keene; Southern NH Walk at the Fisher Cats Stadium in Manchester; and the Seacoast Area Walk where the location is TBD. Registration will begin at 8:30 a.m. with the walks starting at 10 a.m. There will be food, fun and activities for all ages. The goal is to raise over $200,000 for research and Alzheimer programs. With your help we can achieve this goal!

Register your team now by going to www.memorywalknh.org or call 603.606.6590 to receive a great team tool kit.

We are also looking for volunteers who are willing to help with the walk committees or to assist us the day of the walk. If you are interested in helping out or learning more about volunteer opportunities with the Alzheimer’s Association, contact Cindy at 603.606.6590 or e-mail cynthia.rybczyk@alz.org.
Making Our VOICE Heard

Alzheimer’s advocates turned out at primary rallies and gatherings across the state, with a single goal: put the Alzheimer’s issue out in front of the candidates. With national research funding for Alzheimer’s lagging, the message must be carried back to Washington.

Advocates were able to participate in events with John McCain, Mitt Romney, Jonathan Edwards, Hillary Clinton, Joe Biden, Dennis Kucinich, Barack Obama and Rudy Giuliani. Alzheimer’s Association’s Manager of Advocacy and Community Relations Liz McConnell attended more than 40 events for 12 presidential candidates, and spoke directly with 10 of those candidates about the health care impact of Alzheimer’s for families and for the nation. During these meetings, the candidates revealed a personal connection with the disease.

Study Results to be Announced at International Conference

The Alzheimer’s Association International Conference on Alzheimer’s Disease and Related Disorders brings together leading experts in dementia research; and this year is no different.

Among the many researchers reporting results at the Chicago conference July 26-31 are several scientists who have received grants from our Association in the past and have been closely associated with our Chapter: Drs. Dennis Selkoe and Cynthia Lemere of Brigham and Women’s Hospital; and John Growdon, Reisa Sperling and Rudolph Tanzi of Massachusetts General Hospital. Additionally, phase III results on Tarenflurbil (previously called Flurizan) will be announced. If the results, presented by Dr. Robert Green of the BU School of Medicine and involving 1,600 people with mild Alzheimer’s, are positive, they would represent the first positive study for a disease modifying drug—a major step in the development of treatments for the disease.

For more information and opportunities to join clinical studies, see Directory of Research Opportunities for People with Memory Loss and Their Families at www.alz.org/MA, or call the 24/7 Helpline at 800.272.3900.

Planned Giving

Did you realize that there are ways to support Alzheimer’s Association programs and research while...

- Reducing your income or capital gains taxes?
- Receiving a stream of income for your (and your spouse’s) lifetime that will be partially tax-free?
- Helping your heirs minimize costly estate taxes?

You and your family could benefit from any number of Planned Gift options, including:

- Charitable Gift Annuity
- Charitable Lead or Remainder Trust
- IRA Rollover
- Gift of Life Insurance, Real Estate, or other non-cash asset
- Gifts of appreciated stock
- Will provision

For more information, contact Laura Ewing-Mahoney at Alzheimer’s Association, Northeast Regional Planned Giving Office at 603.362.4687 or at laura.ewing-mahoney@alz.org.
Recommended Books for Children

by Rachel Hawk, Vice President, Education

Children are very aware of changes related to Alzheimer’s and other illnesses that cause progressive memory loss, but they are often unable to express their worries or fears. The Alzheimer’s Association, MA/NH Chapter’s 2008 Publications list offers four books for children that may help them better understand and cope with what is happening in their family. Parents find these gentle, colorful books helpful and reassuring.

The Magic Tape Recorder (a story about growing up and growing down) by Joyce Simard. Prices: contributors $8.95, others $9.95. Children may have trouble visiting elders with a dementing illness. This wonderful and colorful book for young children helps them understand, know what to do, feel helpful and enjoy those visits.

Singing with Momma Lou by Linda Jacobs Altman, illustrated by Larry Johnson, hardcover. Prices: contributors/others $16.95. This loving story follows the almost-ten year old Tamika as she visits her beloved grandmother in a nursing home and figures out how to reach beyond memory loss and stay connected.

Still My Grandma by Veronique Van den Abeele, Illustrated by Claude K. Dubois, hardcover. Prices: contributors $14.00, others $16.00. For children ages 4-8, including young readers, this is a lovely story of the special and enduring relationship of Camille and her beloved grandmother who develops dementia.

Wilfrid Gordon McDonald Partridge by Mem Fox, illustrated by Julie Vivas. Prices: contributors $6.95, others $7.95. Youn Wilfrid lives next door to a nursing home and loves Miss Nancy who has “lost her memory.” For young, and even older, children the pictures and story are wonderful.

These and a wide array of books for adults are available from the Alzheimer’s Association, 311 Arsenal Street, Watertown, MA 02472. Postage and handling is $3.00 for the first book, $0.25 for any additional. The full 2008 Publications List can be found at www.alz.org/MA or call us at 1.800.272.3900.

alzheimer’s association®
the compassion to care, the leadership to conquer

A Night of Remembrance

Wednesday May 28, 2008 6:00 to 7:00pm

This special evening is intended for families, friends, and neighbors who have known or now know someone with dementia...and for anyone currently living with memory loss. We hope the evening will provide a quiet place to reflect on cherished memories, grieve what has been lost, and celebrate the living and love that remain with us in spite of the disease. Refreshments will be served.

This event is free and open to the public.

Please RSVP to the Alzheimer’s Association New Hampshire Office (603) 606-6590 or linda.wright@alz.org

Gone yet not forgotten, although we are apart, your spirit lives within me, forever in my heart.
On the Road to Dementia-Friendly Transportation

By Nina M. Silverstein, PhD, Helen Kerschner, PhD, and Marie-Helene Rousseau, PhD

Transportation is one of the major problems faced by people with Alzheimer’s disease and other types of dementia. Though 30-45% of people with dementia continue to drive, the length of time that they continue to drive varies from about three to four years following diagnosis to more than five years. Estimates are that by 2020, approximately 260,000 men age 75 years and older who are driving may have a dementia. The concern is not simply that individuals with dementia should or should not drive, but that driving skills predictably worsen. Public policy strategies are needed that not only identify at-risk drivers, but assure that the cessation of driving does not mean cessation of quality of life. Giving up the keys to ensure safety presents a transportation challenge. However, identifying the types of transportation services that are “dementia friendly” may be an even greater challenge.

The Beverly Foundation, a leader in supplemental transportation programs, has applied their 5 A’s of Senior-Friendly Transportation (see box) to identifying criteria for supportive dementia-friendly transportation. The foundation believes that community-based volunteer driver programs can play a critical role in meeting the needs of adults with dementia. In most instances, if individuals with dementia have not already stopped driving, they might begin looking for other options while they transition from driving. They and their family members rightly look to the community for transportation options that can get them where they need to go. However, it is the degree of “dementia friendliness” of the transportation option that will determine whether transportation enables them to experience a sense of independence, get where they need to go, and enjoy an acceptable quality of life.

The Beverly Foundation has developed a Calculator for Assessing Dementia Friendly Transportation. This easy-to-use calculator allows for a possible score of 25, and rates programs on-the-road to dementia friendliness as Just starting, Out of the garage, On the road, Chugging along, Good show, or Dementia-friendly. Adopting dementia friendliness criteria can provide a way for thinking about and assessing the effectiveness of transportation programs efforts to meet the needs of those with Alzheimer’s, while addressing one of the significant challenges facing those with the disease and their families who are concerned about their safety.

The 5 A’s of Dementia Friendly Transportation

Availability: Transportation services that are available to people with dementia and to their family members — not only are services offered to them, but they are promoted as supportive transportation and advertised in the community.

Acceptability: Transportation services that are acceptable to people with dementia and to their family members — their special needs are attended to with respect to mainstreaming them into the transit system.

Accessibility: Transportation services that can be accessed by people with dementia — services are easy to use because they offer supportive assistance and get them where they need to go.

Adaptability: Transportation services that can be adapted to the needs of people with dementia — services accommodate their needs for schedule reminders and help at destinations.

Affordability: Transportation services that are affordable for people with dementia and their family members — the potential for low-cost operations can enable programs to offer services free of charge, and to be financially sustainable.

Author note: Nina M. Silverstein is Professor of Gerontology, University of Massachusetts, Boston; Helen Kerschner is President & CEO, Beverly Foundation, Pasadena, CA; and Marie-Helene Rousseau is Director of Research, Beverly Foundation.

Do Something “Favorable”

Wedding days are certain to bring an abundance of gifts, showers of love and praise — instead of sending everyone home with a wedding favor they may or may not ever use or appreciate, why not give them something that shows you really care?

Charity donations make a truly touching wedding favor. By making a donation in each guest’s name to a charity of your choice, you’re not only making a beautiful impact on the world, you’re giving guests something they can treasure — the feeling that they’ve made a difference, to you and to the world. For many young couples, this also provides a way to honor grandparents or parents who might be facing the challenges of Alzheimer’s disease.

You can describe the donation on a table card, a small scroll tied with a ribbon, or even a fortune cookie if your statement is brief. It isn’t necessary to describe how much you’ve donated; that’s a personal decision to be made by the couple.

For a donation-in-lieu-of-favors, consider purple wristbands from the Alzheimer’s Association. They’re $2 each — well within the range of most favor budgets — and will give your guests a tangible memento of a worthy, moving cause. For more information, contact Cynthia Rybczyk at 603.606.6590.

Pathways to Independence – 8th Annual NH Conference on Aging

Thursday, May 29, 2008
Radisson Hotel — Manchester, NH
— Open to the Public —

A Lively Day Filled with Informative Speakers and Workshops

Keynote Speaker
Greg Case, Administration on Aging, U.S. DHHS

Conference Fee: Seniors (60 or over): $20
All other registrants: $50

Sponsored by
NH Department of Health and Human Services
Bureau of Elderly and Adult Services
State Committee on Aging

Handicapped parking available
Limited Transportation Available!

Info: call 603.573.3302 or
E-mail nhconferenceonaging@dhhs.state.nh.us
Are you thinking of helping MOVE the Alzheimer’s cause? You don’t always have to ask your friends and family members for a donation in order to raise the much needed funds used for local services and research. You can be creative in your approach and actually have fun with fundraising. These creative ideas are great for young and old alike and can be done anytime….even at your annual family picnic.

The thought is: every penny counts, so no matter what you raise, the idea is to have fun and know your efforts are going to support a larger cause.

Just a few ideas…

**Bake Sale** Get co-workers on board and have everyone bake something and then sell the items to your customers or clients. You can even sell home baked goods at your annual family picnic. Better yet, for those who hate to cook, host a no-bake-sale where participants can pay to actually not cook.

**Car Wash** Great summer project for the kids, most fast food chains or gas stations will be willing to lend their parking lot for the day. Encourage the business to contribute to the efforts with a discount or special offer to those who participate in the car wash.

**Casual Day** Everyone in the office pays $5 in order to wear jeans on a day of their choice.

**Coin Drive** Place jars in public places and encourage employees and customers to empty their pockets of their bulky change…a little can turn into a lot quickly. This is a great project for the kids to coordinate with their schools.

**Garage Sale** Encourage your neighborhood to participate in a garage sale with all proceeds going to the Alzheimer's Association. It’s a great motivation to clean out the attic and closets and you’ll feel good doing it.

For a complete list of fundraising ideas from A to Z contact the Alzheimer's Association at 603.606.6590 or e-mail cynthia.rybczyk@alz.org.

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**Great Gift Idea for Mother’s Day**

“FORGET-ME-NOT” Flower Pin

Designed especially for the Alzheimer’s Association by Newport, RI artist Priscilla Malone (Actual size: 1 1/2” x 1 1/2”). $20 each, plus $2 shipping.

___ Forget-Me-Not Flower Pins ($20 each + $2 shipping/pin) = TOTAL $___________

Name: ________________________________________
Address: _______________________________________
City: ____________________ State: ___ ZIP: ________
Daytime Phone number: _________________________
E-Mail: _______________________________________

___A check to the Alzheimer’s Association is enclosed.
___Please charge my ___ MasterCard ___ Visa
Credit Card #: _____________________ Exp.: ___/ ___

Please include your payment with this form and mail to: Alzheimer’s Association, One Bedford Farms Drive, Suite 105, Bedford, NH 03110 or call 603.606.6590 for more information or to place your order.

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**Early Stage Memory Loss Conference**

**Living Our Lives, Planning Our Futures:**

Resources, Research & Networking Opportunities for People with Early Memory Loss and Their Families

UMass Boston Conference Center, Saturday, June 28, 9:00 am-4:00 pm

— A daylong event dedicated to people with early memory loss —

Registration is free.

For questions and registration, call Nancy Nichols at 617.868.6718 or e-mail nancy.nichols@alz.org.
What is your personal connection with Alzheimer's? Both families have/had immediate family members with Alzheimer's.

Why did you decide to organize a special event? Tim & Paul were holding an annual golf tournament at their work for the employees and vendors. Eventually they both left their place of employment but still wanted to hold a yearly golf tournament and the participants also wanted to continue to play in one. So, they decided to make it a charity event and chose Alzheimer's Association since both families had already had experiences with Alzheimer's. This will be our 7th year holding the tournament.

Is your event open to the public? It is open to the public. We do send out invitations a little early to the people who participated the prior year to give them the opportunity to participate again.

Do you set a fund-raising goal? We don't set a goal. We are very grateful for everything that the players have done to help us raise the money we have over the past few years. Of course, we would always like to improve on the numbers from the previous year.

Have you been able to motivate others to volunteer to help out? We do have quite a few friends and family who help out at the tournament with selling raffle tickets, checking in players, running the Snack Shack on the course, decorating the hall, and setting up for the meal after the day of play.

What is the most satisfying part of your event? Seeing the satisfaction and enjoyment that everyone gets from participating in the tournament, whether volunteering with the work end or playing the 18 holes of golf. Talking to the people afterwards who were so happy to be a part of it. They always want to make sure that they get an invitation to Memory Golf the following year. It is also great to see how it helps family members feel like they can make a difference in dealing with a disease that they themselves cannot control. And we are happy that the tournament generates money that will go to assist in the fight against Alzheimer's, whether it's through research, education, or family/caregiver support.

Event name: (4th Annual) St. Patrick’s Party
Hometown & Event location: Hampton, NH
Event date: March 15, 2008

What is your personal connection with Alzheimer's? William J. McGrail Jr. (Father) died of the disease in April 2003, along with his mother several years earlier.

Why did you decide to organize a special event? William J. McGrail always made St. Patty's Day a very joyous event, huge celebrations, etc. Wanted to carry on the tradition in memory of him and ultimately supporting a good cause.

Is your event open to the public? Has been invitation only.

Do you set a fund-raising goal? To exceed the previous year's.
Overcoming The Stigma and Finding  

It is important to note that the degree to which a person with a cognitive impairment can accept or understand his or her diagnosis varies greatly. Alzheimer’s disease, even in its earliest stages, can affect a person’s ability to have insight and awareness that anything is wrong. In that case it is very important for families to learn as much as they can about the disease so that they may assist the person in the most effective way.

Keeping Secrets

Even those individuals with early-stage Alzheimer’s who are cognizant of their symptoms may want to keep their diagnosis a secret. Some people tend to keep all health matters private. Others may be concerned that people will treat them differently or perhaps avoid contact with them if their diagnosis is known. A person recently diagnosed with Alzheimer’s disease is dealing with changes in self-image and experiencing a wide range of emotions. They may experience feelings of shock, denial, anger, anxiety, guilt, sadness, loneliness, or frustration. Others admit to feeling embarrassed or even ashamed about their symptoms, especially forgetting names or repeating themselves. The caregiver is equally affected, often experiencing the same emotions on behalf of the person. A caregiver may want to protect the person from potential embarrassment or judgment by others and become isolated from friends and family. This desire to protect the person with the impairment also gets in the way of asking for and accepting outside help.

Coming forward about a diagnosis of Alzheimer’s disease is not easy, but there is help available. Through the Alzheimer’s Association’s work with families living with progressive memory loss, we have identified several strategies to help people come to terms with their diagnosis:

- Talk to a trusted family member or friend
- Learn about Alzheimer’s disease through educational programs

• Utilize individual Care Consultation with experts in the field
• Meet other people living with Alzheimer’s disease in a community-based support group or on an internet bulletin board.

• Read personal accounts of families living with Alzheimer’s disease
• Seek individual or family counseling
• Treat the symptoms of depression, both for the person with the disease and the caregiver
• Plan for the future, particularly legal and financial planning
• Participate in research

Taking the Journey

Here is one early stage person’s story about her journey to acceptance:

Margaret had recently retired from her job as a popular schoolteacher in the town that she and her husband had lived for many years. She had always been a very outgoing person who belonged to many clubs and organizations. After Margaret’s diagnosis of Alzheimer’s disease, she began to limit her social engagements and other activities. Even though she was in the early stages of Alzheimer’s disease, she was concerned that her friends might notice that something was wrong with her. She was dealing with significant communication difficulties, particularly word finding difficulties and repetition. When she did see her family and friends, it would take considerable effort to mask these symptoms, and she was not able to enjoy herself. Her husband was able to interest her in attending an educational program offered by the Alzheimer’s Association called Taking Control of Alzheimer’s disease. This program is designed specifically for early-stage persons like Margaret. At the program, she had the opportunity to meet other people living with Alzheimer’s disease who had been able to tell others about their diagnosis. By the end of the four-week program, she told the instructor that she had stopped trying to hide her communication difficulties and short-term memory loss. Instead she asked others to be patient with her because of her memory impairment. If people wanted to know more, she would tell them that she has been diagnosed with Alzheimer’s disease. Now that she was open about her diagnosis of Alzheimer’s disease, she was amazed how much more energy that she had to enjoy her life.

Here is one caregiver’s story that shows the powerful impact of stigma:

Ann is the primary caregiver for her husband, George, who was diagnosed with Alzheimer’s disease about five years ago. George is a retired physician. Both George and Ann have always been very active in their church and served on the boards of many community organizations. Although George had diagnosed many patients with Alzheimer’s disease in his practice as a physician, he had always denied any cognitive problems in himself. Not wanting to upset George or change his stature in the community, Ann did not tell anyone about his diagnosis. Instead she came up with elaborate excuses for their withdrawal from community organizations and lack of attendance at church. Even though she was not able to leave George alone at all, she refused any respite care for fear that gossip about his condition would start. Her only source of support was occasional e-mail contact from the Alzheimer’s Association Helpline.

VISIT US ONLINE: WWW.ALZ.ORG/NH
in which she acknowledged feeling depressed and lonely.

**Being Candid Opens Doors**

Overcoming the power of the stigma associated with dementia takes a tremendous amount of courage, but hiding a diagnosis from others can be detrimental for the affected person and his or her family. Trying to cover up the symptoms can be exhausting for both the caregiver and the person and often leads to withdrawal from activities of interest and social isolation. This is unfortunate since involvement in meaningful activity and socialization actually helps the person living with dementia to function at their best and helps to improve symptoms of depression and anxiety.

Being candid about a diagnosis of Alzheimer’s disease and related disorders opens the door for assistance and support from others. Alzheimer’s disease can be a long and challenging journey on which no person or family should go alone. Family and friends are often willing to help out if they are informed and feel more comfortable relating to the person living with Alzheimer’s disease.

Speaking out about Alzheimer’s disease and related disorders is our most powerful weapon in the fight to eliminate stigma, increase awareness, improve care and treatment and ultimately find a cure. Individuals and families who have been directly affected by progressive memory loss are especially effective in increasing public awareness, even just by their willingness to come forward. There are many ways that people can help and it starts with talking to close family and friends. When they share their knowledge and experience with people they know, a chain reaction begins. Other ways to increase awareness are by speaking to someone in your faith community, writing letters to public officials, participating in community events hosted by the Alzheimer’s Association such as Memory Walk, Memory Ride and others. There are also opportunities to participate in public speaking and media interviews. By sharing your experience you can help to debunk some of the false beliefs and educate policy makers about the needs of individuals and families living with dementia. These efforts have a huge impact on funding for research and services for individuals and families. Perhaps most importantly, by speaking out and becoming a champion for the cause, you inspire others to do the same so that the stigma associated with dementia can be eliminated.

Editor’s note: Families can access supports and programs mentioned in the article through the Alzheimer’s Association, MA/NH Chapter. For

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**Tips for Late Stage Care: Communicate Your Caring**

Consider the wide range of possible ways to communicate with someone. Even in the later stages of Alzheimer’s disease, don’t assume that if the person is quiet that you should withdraw. You should, indeed, make every effort to communicate. Open shades in the morning, keep the room bright and cheerful, fresh and clean; even think about adding something that smells nice. Tuck a soft stuffed animal next to them in the bed.

- Talk, quietly and rather slowly, tell stories, and reminisce, sing (who cares how it sounds?) Respond to their words or sounds. Don’t be afraid to be cheerful.
- Look into their eyes, smile, reassure: “I’m here. I’ll take care of you. I love you.”
- Put your arms around them, hold hands, gently stroke their cheek or arm.
- Bring small chores into the room and talk while accomplishing them.
- Listen and watch body language for expressions of discomfort or pain, fear, and frustration as well as signs of relaxation, peace and calm.
- Leave the room if you get upset or angry.
- Play music, but not constantly, watching for what he/she seems to like.
- Have a comfortable chair for yourself, and sit nearby.
- Notice what increases those good feelings and repeat!
- Encourage your visitors to do these things, also.

Chances are no one else will ever know how much you have done to make life easier for the person you care about; how much being truly cared for means to them. But you will.
Get the Emotional Support You Need

We have many support groups, at various times and locations. Check to see if there is a group close to you that fits your needs. If you prefer, call our 24-hour Helpline at 1.800.272.3900. Support groups are independently run and this listing should not be construed as a recommendation.

Why did you become a volunteer for the Alzheimer's Association?

I became a volunteer after attending the Alzheimer's Association Open House in August 2007. The people at the Association were impressed with me, and the way I was handling my illness. I was impressed with them and was happy to help them out when they approached me to be interviewed and to tell my story. I even had an opportunity to speak to Senator John McCain at a rally during the New Hampshire Primary in January!

What keeps you motivated?

I feel that if I keep moving and doing things that is a big help. I am now going to the Elliot Senior Day Care two days a week. It gets me out of the house and my wife, Harriet's, hair! In addition to the day care, we have a cocker spaniel named Shanna who needs to go out frequently during the day. That is part of my job. I have had some rough spots when I was coming off Aricept and going on to Exelon, but they seem to have smoothed out somewhat. I am also a model electric train enthusiast and still attend model train shows whenever possible. I cannot drive myself any more and can’t stay for two days because I get tired more easily.