Peggy and Michael Powell know firsthand the unique circumstances of early-onset Alzheimer's disease. The Escondido, California couple noticed changes in Peggy's work as a kindergarten teacher nearly four years ago, when activities such as calculating grades and collecting money for a class pizza party became increasingly challenging. Then, after years of dancing in a performance of The Nutcracker, one day Peggy could not remember the steps to the dance. These and other changes initiated an arduous process of discovery for the Powells, who sought an explanation for why Peggy, in her early 50's, was having difficulty with her memory. They quickly realized that common assumptions about a younger person experiencing memory loss can create challenges in obtaining a diagnosis and finding acceptance from friends and relatives. Because of Peggy's young age, doctors first suspected that the changes were due to something psychological or perhaps hormonal. After ruling out those possibilities, doctors informed the couple in May of 2006 that this was Alzheimer's disease. Many people close to the Powells were in disbelief; they denied the news and told the couple that the doctors must not have known what they were talking about. Peggy and Michael had trouble accepting the diagnosis themselves, and they sought a second opinion by enrolling in the University of California, San Diego's Shiley-Marcos Alzheimer's Disease Research Center. A thorough evaluation confirmed the initial findings: at age 53, Peggy had early-onset Alzheimer's.

The term early-onset refers to Alzheimer's that begins to affect individuals when they are younger than 65. In the United States, up to 10 percent (or about 400,000 people) of those with Alzheimer's have early-onset. While most public attention goes toward later-onset dementia, developing the illness at a relatively young age creates distinct challenges for the diagnosed person and his or her loved ones. For Peggy and Michael, actions that would typically take place in later stages of life – retirement, long-term care planning – have arrived in advance. Moreover, with two daughters currently in their 20's, they have faced the added financial burden of 

(continued on page 2)
helping put kids through college while addressing complex medical and social needs. Although there are some support services available to people impacted by Alzheimer’s, many of these services are not tailored to a younger population.

Michael, age 58, works full-time as an elementary school teacher, leaving the house at 5:30 each morning and returning home at around 4:30 p.m. Seeking to understand Alzheimer’s as well as possible, he takes interest in educational programs offered in the community. However, when these programs take place in the daytime, he and other working care partners are unable to attend. The Powells have also had to search for meaningful activities for Peggy, who stopped teaching two years ago but wants to maintain a dynamic lifestyle. They realized that adult day centers did not provide her with a peer group of younger, more physically active individuals. These types of concerns are very common among those with early-onset Alzheimer’s.

Fortunately, Peggy has found two programs in San Diego – Out & About, a social and cultural outings program based at the Shiley-Marcos Alzheimer’s Disease Research Center, and Friday Club, a social program combining cognitive stimulation, exercise, volunteer work, and outings at Silverado Senior Living in nearby Encinitas – that are more to her liking. Having always been a friendly, active person, Peggy says, “I like being around the people” during Out & About and at Friday Club. On other days during the week, Peggy and a neighbor go on walks or go swimming at the gym, where she recently set a personal record for number of laps in a row. These activities appear to have eased Peggy’s struggle to adapt to Alzheimer’s: “There’s help,” she says. “It is a terrible thing, but after a while you get used to it.”

Although some close friends have drifted away over the past two years, the Powells have made new connections through participating in a support group at their local chapter of the Alzheimer’s Association for early-onset couples. Michael also utilizes several online support networks. He describes the couple’s approach as “living each day.” This suggests both pragmatism – being able to adapt to ever-changing circumstances – and a focus on quality of life. When reflecting on Alzheimer’s disease, Michael says, “It doesn’t seem to help to think about it as either positive or negative. It comes back to living: what are we doing in this moment? Thinking about it is something else. Thinking about the way it should have been, or what it could have been, or what it was like – it’s like okay, it’s time to be here. We want to live.”
Employment, Disability, and Dementia
A Survey to Explore the Issues

Although many people with Alzheimer’s disease (AD) or a related dementia are diagnosed in their retirement years, there are some who are actively involved in their work or profession when symptoms begin. The onset of symptoms often results in a period of challenging adjustments in the workplace and eventually the need to retire due to disability. Has the onset of AD or a related disorder affected your ability to continue your employment and receive health insurance or other related benefits? If so, you might be able to provide valuable information about your experience.

The Alzheimer’s Association’s Early-Stage Advisory Group (comprised of persons with AD who advise the National Alzheimer’s Association) has put together a survey for people with early-stage Alzheimer’s in order to gather data relating to how a diagnosis of AD affects employment and the ability to receive all the benefits that one is entitled to. The survey can be completed with the assistance of a care partner if needed, and can be done online at http://alz.earlystage.sgizmo.com. The Alzheimer’s Association will be collecting survey data **thru the end of April** and then will release a white paper after analysis of the results. The results may help the Alzheimer’s Association as they advocate to Congress on behalf of persons with AD.

Come to Washington DC for the Alzheimer’s Association Public Policy Forum
May 12-14, 2008

Election season creates excitement and is a time of changing political landscapes. It is also a unique opportunity to increase concern and awareness about Alzheimer’s on Capitol Hill. Lawmakers of both parties are developing their policy agendas in light of the 2008 election, and efforts to improve the health care system are expected to be a top priority issue in the fall. We need to make sure Alzheimer’s issues are part of the debate on health care.

The 2008 Public Policy Forum is just around the corner. Make your plans now to join us in Washington to learn how the outcome of the elections will impact Alzheimer’s issues in Congress, meet your lawmakers, and enhance your advocacy skills. The Public Policy Forum is also a great time to meet new friends, network with fellow advocates, and honor those who have been touched by Alzheimer’s at the candlelight vigil. Registration information is at http://www.alz.org/forum. There are 50 free registrations for persons with early-stage Alzheimer’s and scholarship support is available through Alzheimer’s Association chapters.

May 12th will also feature the last in a series of national early-stage town hall meetings for persons with Alzheimer’s to speak out about their perspectives and concerns. This meeting will be from 9:00am-noon on May 12th at the same hotel as the Public Policy Forum and is free of charge. For more information, see http://www.alz.org/townhall/meetings.asp or call Jeffrey Carpenter at 312-377-6620.
Talking to Children and Teens About Alzheimer’s

For many people facing Alzheimer’s or a related disorder, there are younger people in their lives who may be impacted by the effects of symptoms on a loved one. If you were diagnosed at a young age, you may have children still living at home or just getting off to college or employment. If you are older with Alzheimer’s, there could be grandchildren in your life or young extended family members or friends.

Young persons may respond to Alzheimer’s in a number of different ways. Some young people may feel closer to you and want to be involved in helping out or having a role in caregiving. Others may feel frightened or stressed by your symptoms and not know how to respond. Some children may not know how to explain your symptoms of Alzheimer’s to their peers or may lack educational information themselves.

Your own attitude about Alzheimer’s will likely influence the response of children to your symptoms. If you are stressed or angry, the symptoms may seem more frightening or upsetting to the young person. If you are able to maintain a sense of humor or openly discuss your memory loss, this will help the younger person be at greater ease. Laughter is always good medicine and often helps to bring people closer.

Many children and teens want to be of help, but don’t know what to do. If a young person wants to be helpful, think of ways he or she might be able to assist you. This could be running an errand or making you a cup of tea. Show your appreciation so that the young person feels valued and useful. You can also think of fun things that you can do together such as creating a photo album or scrapbook, playing games, gardening, or taking walks together.

Younger people are often inquisitive and can benefit from open communication. Children can ask very direct questions, while teens may be curious, but a bit more self-conscious about initiating discussion. Although there is a great deal of information available about Alzheimer’s disease, there is much less that is written directly to the needs of children and teens. The National Alzheimer’s Association maintains a website that is written directly to kids and teens and provides easy-to-read information about Alzheimer’s as well as video and written resources at: http://www.alz.org/living_with_alzheimers_just_for_kids_and_teens.asp.

The Alzheimer’s Foundation of America also has a comprehensive website devoted specifically to teens that includes a teen message board and chat room at: http://www.afateens.org/index.html.

Teens are very savvy about the internet and acquiring information. Although this can be beneficial, you also want to make sure that children receive accurate information and constructive support. There are a growing number of books about Alzheimer’s written specifically for children or teens. Check with your local Alzheimer’s organizations or library for helpful resources and recommendations.
NEW RESOURCES
By Sherry Dupuis and Jennifer Gillies

The By Us For Us Guides

When Brenda Hounam was diagnosed with Alzheimer’s nearly eight years ago, she realized how little information was available for persons living with early stage memory loss. This omission inspired her with an idea - to develop a series of resources specifically designed by and for persons with dementia. In 2006, she approached her peers with her idea and was astounded by their enthusiasm and support. Through Brenda’s contacts at the Alzheimer Societies of Brant and St. Thomas and the Murray Alzheimer Research and Education Program (MAREP) at the University of Waterloo, Brenda connected with persons living with dementia from all around Ontario, Canada to work on what is now aptly called the “By Us For Us” guides. These guides provide tips and strategies for managing daily challenges and enhancing well-being for persons living with memory loss. With the support of MAREP and the Alzheimer Society of Brant, three By Us For Us (BUFU) guides have been developed. They include information gathered from persons living with early stage memory loss through support group meetings, individual contact, and open-ended, mail-out questionnaires. All three guides have been well received in Canada and are being requested by individuals and organizations around the world.

The first guide, Memory Workout, encourages persons with dementia to develop and maintain regular "workouts" for the brain so as to enhance functioning while engaging in enjoyable activities. The second guide, Managing Triggers, outlines the main triggers experienced by persons with memory loss and offers solutions for how they and their partners in care can manage and alleviate them. As Brenda Hounam states in the introduction to the guide, “Understanding our triggers and the causes of them can be very difficult but it’s so important if we hope to be able to reduce the incidence of them or learn how to respond to them more effectively”. The third guide, Enhancing Communication, outlines the challenges experienced when communicating with family, friends, and health care professionals. It provides tips on how to enhance communication and emphasizes the importance of using a wide range of communication strategies.

The BUFU team is developing two new guides in 2008 to complete the series. What makes these guides so innovative and meaningful is that they are resources developed by and for persons with memory loss and they enable partners in care to gain a better understanding of the direct experiences and needs of persons with dementia. As one of the BUFU team members states in the Enhancing Communication guide, “We hope that through this guide, you can gain a better understanding of our experiences and gain tips on how we can all work together to enhance our lives together.” – Gail Robinet

The guides are free to persons with dementia and their care partners and can be ordered through the MAREP website http://marep.uwaterloo.ca/products/bufu.html or by calling 519-888-4567, ext. 32920.
Research Updates

International Genetics Project

The National Cell Repository for Alzheimer’s (NCRAD) is a resource facility at Indiana University Medical Center in Indianapolis, Indiana and is funded by the National Institute on Aging. The purpose of NCRAD is to provide resources to aid researchers around the world in identifying genes that contribute to Alzheimer’s and related dementias. In order to conduct these important investigations, scientists require genetic material (DNA) from individuals and families who have at least two relatives diagnosed with Alzheimer’s or a related dementia. It is not necessary for study participants to go to the NCRAD site in Indiana. Families from around the United States and any region in the world may be eligible to participate.

As part of a family’s participation in this study, you may be asked to provide family history information, documentation of a diagnostic evaluation for Alzheimer’s or a related dementia, and a blood sample. You also may be contacted periodically for additional or updated family information.

One other way that scientists can learn more about Alzheimer’s is through the careful examination of brain tissue of persons with dementia at the time of death. NCRAD can work with families to arrange an autopsy plan in advance, and will help cover the associated costs.

For more information, please contact the National Cell Repository for Alzheimer’s Disease at 1-800-526-2839 or by email at alzstudy@iupui.edu. You can also visit their web site at http://ncrad.iu.edu.

Response to Dementia Diagnosis

Researchers at Washington University in St. Louis, Missouri followed 90 individuals and their care partners who came to the University’s Alzheimer’s Disease Research Center for evaluation. Of these individuals who were evaluated, 69% eventually received a diagnosis of Alzheimer’s disease. Through pre and post diagnostic questioning, researchers found that both persons diagnosed with Alzheimer’s and their care partners felt relief after hearing the diagnosis rather than the feelings of anxiety or depression that physicians might fear. The researchers conclude that it is helpful for physicians to clearly make a diagnosis of Alzheimer’s so that a family can have an explanation for symptoms and can be proactive in seeking possible treatment or in planning for the future.

Passive Immunization Update

Elan Corporation and Wyeth Pharmaceuticals have begun recruitment across multiple sites in the United States and Canada for their two Phase 3 clinical trials of bapineuzumab (AAB-001). This treatment, called passive immunization, infuses antibodies directed against the beta-amyloid protein that forms damaging plaques in the brain of persons with Alzheimer’s. In previous clinical trials, Elan tried using an “active immunization” approach that prompted study participants to produce their own antibodies, but a small group of individuals developed brain inflammation. The modified “passive immunization” approach being used in this current trial has not resulted in the same complications and holds promise for slowing the progression of Alzheimer’s. For more information on this study, call Elan Corporation at 1-866-446-5463.
Many people with Alzheimer’s want to maintain as much independence as possible, but also need to address important safety issues. It is not uncommon, even in the earlier stages, to experience episodes of confusion or disorientation. A walk in a familiar neighborhood can suddenly seem foreign if you go off your normal route. Or coming out of a restroom in an airport, you take a wrong turn and pretty soon, you’re separated from your traveling companion and lost in the crowded hustle and bustle.

Since its inception in 1993, the Alzheimer’s Association’s Safe Return program has helped to reunite more than 13,000 people with dementia with their families and care partners. By wearing a specific ID bracelet or necklace, authorities can help to identify you as a person with memory loss and get you immediate help. Recently, Safe Return partnered with the well-recognized MedicAlert program to create a 24-hour emergency assistance program for persons with Alzheimer’s who may be lost or otherwise in need of emergency help. Wearing an emergency alert bracelet can actually enhance your independence by giving the added security of help if needed when you are out on your own. To find out more about this valuable program, call your local chapter of the Alzheimer’s Association or find information on the website at: http://www.alz.org/we_can_help_medic_alert_safereturn.asp

We asked people with Alzheimer’s:

Have you done anything to make your life a little safer in the face of memory loss or other symptoms?

Here are some of the answers:

“I still like to garden, but I don’t use all of the electric and gas-powered stuff that I used to. It just moves too fast so I use hand tools now. It’s a lot more work!”

“I take a cell phone with me when I walk so my wife can find me.”

“My husband got me a Safe Return bracelet a few years ago. I didn’t like it at first, but I’m used to wearing it now and it’s probably a good idea.”

“I just do whatever my wife says! That keeps me safe from a lot of stuff.”

“I keep a nightlight on in the bathroom so I don’t trip in the middle of the night. Sometimes I feel like I can get lost in my own house, so the light also helps to point the way.”

“I gave up driving. That was really rough, but I didn’t want to hurt someone.”

“I just use the microwave now instead of the stove. When I burnt the second teakettle, my daughter said that was enough!”

I don’t think my life is that different with Alzheimer’s. I never was a big risk taker, so it’s not like I’m going to jump off a cliff now.”

“I actually did jump off a cliff! It was for my birthday and I went off the cliffs at the beach strapped in with an expert hang glider who did all the work. It was great! It was safe enough because he knew what he was doing. Gotta keep living!”
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