What We Can Learn from Cancer Research

By Michael Rafii, MD, PhD
Director, Memory Disorders Clinic
Associate Medical Core Director
Alzheimer’s Disease Cooperative Study
University of California, San Diego

“The greatest need we have today in the human cancer problem, except for a universal cure, is a method of detecting the presence of cancer before there are any clinical symptoms” - Sidney Farber, November, 1962.

Dr. Sidney Farber is regarded as the father of modern cancer chemotherapy, and after whom the Dana-Farber Cancer Institute is named. He understood that to treat cancer, even to prevent it, early detection is essential. In the last 50 years, significant advances have been made in this regard.

Oncologists today will tell you that the treatment of early stage cancer is very different from the treatment of widely spread, metastatic cancers, even with the same type of cancer. It is also widely recognized that early treatment is much more successful than later treatment. The key to successful treatment of cancer is early detection.

One example of this type of success in early detection of cancer is the Papanicolaou test or so-called “pap smear.” In 1952, 150,000 women had pap smears done as part of a clinical trial and were followed over time. About 500 of these women were discovered to have invasive cancer at that time, and were treated accordingly. Interestingly, another 500 women who were completely asymptomatic had precancerous lesions that were curable by a relatively simple surgical procedure. These women were on average, twenty years younger than the women with the invasive lesions. The pap smear, in effect, allowed for cancer detection, and treatment twenty years earlier than previously possible. Since then, the discovery of the human papillomavirus (HPV) as the cause of almost all cases of cervical cancer has led to development of a vaccine against HPV, which in turn, has led to prevention of cervical cancer.

In primary prevention, a disease is prevented by stopping its cause, such as HPV vaccination that reduces the risk for cervical cancer. In secondary prevention, a disease is prevented by screening for its early, presymptomatic stage. In the case of the pap smear, detection of abnormal cervical cells allows for prevention of cervical cancer.

In Alzheimer’s disease, the question is, are we detecting the disease early enough to make a difference? One way to answer this will be to look at the effect of the anti-amyloid drugs, including bapineuzemab and solaneuzemab, to see if they have any effect on biomarkers that demonstrate the presence of early AD.

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What We Can Learn from Cancer Research continued ...

Even if the phase 3 studies of these drugs did not reach their clinical endpoints, a strong enough effect in reducing beta-amyloid will indicate that we are headed in the right direction and that perhaps with earlier detection and treatment could prevent the dementia stage of AD.

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Report Reveals Negative Perceptions About People with Dementia

Seventy-five (75) percent of people with dementia and 64 percent of caregivers believe there are negative associations for those diagnosed with dementia in their countries, according to a survey fielded by Alzheimer's Disease International and published today in the *World Alzheimer Report 2012: Overcoming the Stigma of Dementia*.

"The report reveals that people with dementia and their care partners often feel disconnected from society, and sometimes even by their own friends and family members," said Beth Kallmyer, MSW, vice president of constituent services at the Alzheimer's Association. "The misconceptions and stigma create unnecessary barriers to progress such as improving care and support services and increasing funding for research."

In the current report, nearly one in four people with dementia (24 percent) who responded to the survey said they hid or concealed their diagnosis, citing stigma as the main reason. They expressed concerns that their thoughts and opinions would be "discounted and dismissed," and that they would be "treated more positively" if they did not reveal their diagnosis.

The authors noted that, social exclusion was a "major theme" with 40 percent of people with dementia in the survey reporting they have been avoided or treated differently because of their dementia. Respondents said their friends and family "say they don't know how to behave 'normally' around me anymore," and many have "drifted away."

A survey respondent with dementia from the United States said: "It's very interesting to see how people close to me act. It's almost as if they are afraid of bringing up the subject. Being a cancer survivor, I know that I was constantly asked how I was doing while I was going through treatment. With Alzheimer's, no one asks."

The report found that when people with dementia are able to make new connections, it is often with people in similar circumstances. Sixty-six percent of survey respondents who have dementia said that they have made friends who are connected to dementia, often finding each other through community-based support groups, online chat or bulletin boards, and through local and regional Alzheimer's associations.

"People with dementia, especially in the early and middle stages, can take part in many everyday activities. They have the same needs as everyone else for social interaction and engagement in meaningful activities, even in the later stages of the disease. We encourage people living with Alzheimer's or another dementia to be involved in making decisions that affect them for as long as they can, to help maintain their autonomy, dignity and self-esteem," Kallmyer said.
Facing Stigma
In response to the report and to honor of World Alzheimer's Month, the Alzheimer's Association unveiled tips for coping with stigma created by people living with the disease. Current and former members of the Alzheimer's Association National Early-Stage Advisory Group developed these tips based on their personal experiences:

- **Be open and direct.** Engage others in discussions about Alzheimer's disease and the need for prevention, better treatment and an eventual cure.

- **Communicate the facts.** Sharing accurate information is key to dispelling misconceptions about the disease. Whether a pamphlet or link to online content, offer information to help people better understand Alzheimer's disease.

- **Seek support and stay connected.** It is important to stay engaged in meaningful relationships and activities. Whether family, friends or a support group, a network is critical.

- **Don't be discouraged.** Denial of the disease by others is not reflection of you. If people think that Alzheimer's disease is normal aging, see it as an education opportunity.

**Be a part of the solution.** Advocate for yourself and millions of others by speaking out and raising awareness.

The report also included 10 recommendations to enable governments and societies to tackle stigma, including encouraging greater public education. Nearly half of the survey respondents pointed to increasing education and raising awareness about Alzheimer's and dementia as a much-needed, high-priority action. Other recommendations are to provide more opportunities for people with dementia to share their experiences and ensure that they are included in everyday activities.

*The contents of this article were published by the Alzheimer’s Association on September 24, 2012 and are reprinted here with permission.*

Latest Alzheimer’s Research Progress Report Released

2010 Alzheimer’s Disease Progress Report: A Deeper Understanding, highlights important developments and directions in federally funded research. The booklet is prepared by the National Institute on Aging (NIA), which leads the effort supporting Alzheimer’s research.


- **Contents of this publication include:**
  - Risk for developing Alzheimer’s including genetics
  - Neuroimaging and biomarkers that detect and track the disease
  - Research into new treatments
  - Lifestyle factors that may worsen or protect against the disease
  - Help for caregivers
  - Animation showing the progression of Alzheimer’s in the brain
  - Video interviews highlighting new insights into the disease
Some Things the Authors Learned About People with Dementia...

Excerpted from Alzheimer's Disease International’s
World Alzheimer Report 2012: Overcoming the Stigma of Dementia

“The people with dementia who participated in this survey are courageous, candid and have shared meaningful contributions about how they can be better treated by society.

- We learned that people with dementia are aware that other people are afraid to talk to them. They would like to be included in conversations. For some people with dementia it is acceptable and encouraged to ask about their memory loss.

- People in the survey have suggestions for how you can better communicate with them; as the person with dementia best knows his or her own limitations. Survey respondents mentioned that crowded places are loud and distracting. It may be difficult for the person to have conversations. Some will ask for help remembering words they forget, and some prefer you not correct them, but instead understand the meaning of their message.

- People with dementia also shared how disheartening it is that people avoid or ignore them. Others, whether family, friends, strangers or health professionals tend to address their carer and no longer include them in the conversation.

- While people with dementia are aware of their own limitations, they would like their social circles to adapt and accommodate to their new level of abilities. One example from the survey was the gentleman who mentioned he still enjoys playing golf with his friends however keeping score has become less important as he is undoubtedly aware that he can no longer do so.

People with dementia also shared the fact that they feel more isolated and withdrew from regular activities, either because they could not keep up or because they wanted to protect their friends from having extra burden. Friends will need to take more of the initiative for the person with dementia. Providing transportation, maintaining visits in the home, and providing social opportunities were mentioned by people with dementia in their examples.

We must listen to what people with dementia say, and act on it. We have based recommendations of this report on their responses (see report Chapter 4).”
Alzheimer’s Disrupts Brain Networking

By Michael C. Purdy
Senior Medical Science Writer
Washington University School of Medicine

Scientists at Washington University School of Medicine in St. Louis have taken one of the first detailed looks into how Alzheimer’s disease disrupts coordination among several of the brain’s networks. The results, reported in The Journal of Neuroscience, include some of the earliest assessments of Alzheimer’s effects on networks that are active when the brain is at rest.

“Until now, most research into Alzheimer’s effects on brain networks has either focused on the networks that become active during a mental task, or the default mode network, the primary network that activates when a person is daydreaming or letting the mind wander,” says senior author Beau Ances, MD, assistant professor of neurology. “There are, however, a number of additional networks besides the default mode network that become active when the brain is idling and could tell us important things about Alzheimer’s effects.”

Ances and his colleagues analyzed brain scans of 559 subjects. Some of these subjects were cognitively normal, while others were in the early stages of very mild to mild Alzheimer’s disease. Scientists found that all of the networks they studied eventually became impaired during the initial stages of Alzheimer’s.

“Communications within and between networks are disrupted, but it doesn’t happen all at once,” Ances says. “There’s even one network that has a momentary surge of improved connections before it starts dropping again. That’s the salience network, which helps you determine what in your environment you need to pay attention to.”

Other networks studied by the researchers included:

- the dorsal attention network, which directs attention toward things in the environment that are salient;
- the control network, believed to be active in consciousness and decision-making; and
- the sensory-motor network, which integrates the brain’s control of body movements with sensory feedback (e.g., did the finger that just moved strike the right piano key?).

Scientists also examined Alzheimer’s effects on a brain networking property known as anti-correlations. Researchers identify networks by determining which brain areas frequently become active at the same time, but anti-correlated networks are noteworthy for the way their activities fluctuate: When one network is active, the other network is quiet. This ability to switch back and forth between networks is significantly diminished in participants with mild to moderate Alzheimer’s disease.

The default mode network, previously identified as one of the first networks to be impaired by Alzheimer’s, is a partner in two of the three pairs of anti-correlated networks scientist studied. “While we can’t prove this yet, one hypothesis is that as things go wrong in the processing of information in the default mode network, that mishandled data is passed on to other networks, where it creates additional problems,” Ances says.

It’s not practical to use these network breakdowns to clinically diagnose Alzheimer’s disease, Ances notes, but they may help track the development of the disease and aid efforts to better understand its spread through the brain.

Ances plans to look at other markers for Alzheimer’s disease in the same subjects, such as levels in the cerebrospinal fluid of amyloid beta, a major component of Alzheimer’s plaques.

Emergency Preparedness for Loved Ones with Alzheimer’s Disease

People with Alzheimer’s disease can be especially vulnerable in disaster situations. Their impaired memory and reasoning may severely limit their ability to cope. For caregivers, it is important to have a disaster plan that incorporates the special needs of the person with Alzheimer’s.

“Riding it out” at home

In some situations, you may decide to stay at home during a natural disaster. Plan ahead to meet your family’s needs and those of the person with Alzheimer’s for at least 3 days to a week. Include supplies and backup options in case you lose basic services. Refer to information from organizations such as the Federal Emergency Management Agency [1] (FEMA) and the American Red Cross [2] to make a general disaster plan.

You also will need special supplies for the person with Alzheimer’s. Assemble a kit and store it in a watertight container. The kit might contain:

- warm clothing
- sturdy shoes
- spare eyeglasses
- hearing aid batteries
- incontinence undergarments, wipes, and lotions
- pillow, toy, or something the person can hold onto
- medications
- favorite snacks and high-nutrient drinks
- zip-lock bags to hold medications and documents
- copies of legal, medical, insurance, and Social Security information
- physician’s name, address, and phone number
- recent photos of the person with Alzheimer’s

Also as part of your disaster planning, have practice drills, with each member of the household performing specific tasks. Do not give the person with Alzheimer’s responsibility in the plan. Assign somebody to take primary responsibility for him or her.

Because the needs of a person with Alzheimer’s will change as the disease progresses, periodically update your plan to reflect these changes. For example, he or she is likely to become less mobile in the later stages of the disease. How will that affect your plan?

If you must leave home

You may need to move to a safer place, like a community shelter or the home of a family member. Consider how you will get the person with Alzheimer’s disease to go quickly and calmly. Be ready to use tactics that have worked in the past.

During relocation, the person with Alzheimer’s might become very anxious and start to behave erratically. Remain as calm and supportive as possible. He or she is likely to respond to the tone you set. Be sensitive to his or her emotions. Stay close, offer your hand, or give the person a reassuring hug. Do not leave him or her alone.
To plan for an evacuation:

- Know how to get to the nearest emergency shelters. Some areas have shelters for people with special needs. Local Red Cross chapters can direct you.
- If you don't drive or driving is dangerous, arrange for a family member, friend, neighbor, or emergency service to transport you.
- Make sure that the person with Alzheimer's is wearing an identification bracelet and/or that identifying tags are sewn into articles of clothing.
- Take both general supplies and your Alzheimer's emergency kit.
- Bring your cell phone charger and keep the phone charged. Save emergency numbers to your phone, including the Alzheimer's Association Safe Return [3] phone number (1-800-625-3780), if you participate in that program.
- Plan to keep neighbors, friends, and family informed about your location. Give them your phone numbers and a list of emergency numbers.
- Be sure that other people have copies of the person's medical records. If necessary, they can provide these records to emergency medical staff to ensure that the person receives appropriate treatment and care.
- Pack familiar, comforting items for the person.
- If conditions are noisy or chaotic, prepare to find a quieter place.
- Prepare to prevent wandering. Many people with Alzheimer's disease wander, especially under stress.
- If possible, plan to take along the household pet to comfort the person.

If you become separated

You should not leave a person with Alzheimer's alone, but the unexpected can happen. Avoid asking a stranger to watch the person if possible. Also, do not count on the person with Alzheimer's to stay in one place.

To plan for possible separation:

- Provide local police and emergency services with photos of the person and copies of his or her medical documents, so that they are aware of the person's needs. Be ready to alert them if you and the person in your care become separated.
- Be sure that the person with Alzheimer's wears an identification bracelet.
- Contact your local Alzheimer's Association chapter and enroll the person in the Medic Alert + Safe Return program [3]—an identification and support service for people with Alzheimer's disease who may become lost or injured.
- Make plans with trusted people who can help the person with Alzheimer's. Educate them about the person's disabilities. Give examples of simple instructions that the person may follow.
- Give a trusted neighbor, friend, or relative a house key and a list of emergency phone numbers.

Alzheimer’s Disease Education and Referral Center
P.O. Box 8250
Silver Spring, MD 20907-8250
1-800-438-4380 (toll-free)
1-800-222-2225 (TTY/toll-free)

Source URL: http://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-and-disaster-preparedness
The goal of the Alzheimer’s Disease Neuroimaging Initiative Study is to learn how to stop the progression of mild cognitive impairment (MCI) and Alzheimer's disease in future generations. Information from the study might, in the future, lead to new treatments.


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