



ALZHEIMER'S DISEASE CENTER



"Dedicated to improving the health, well-being and quality of life of patients and their families."

QUARTERLY

**Multi-disciplinary panel to address the ethical, legal and social issues raised when persons with dementia vote.**

by Bryan James, MBioethics

Voting is a fundamental civil right of all adult citizens of the United States. But adults with Alzheimers disease and other dementias may lose the ability to exercise this right as their cognitive impairments progress. This presents a problem to family members and health care professionals who are responsible for the well-being of persons with dementia.

A series of questions frame the nature and scope of this problem: How should we understand "the capacity to vote" and how can a person assess another person's "capacity to vote?" What kind of assistance in voting is appropriate to provide to a person with cognitive impairment? Is it permissible for a close family member to vote for a person with dementia? What role should long-term care staff have in provid-

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**Fairwell from the Editor**

Dear Friends of the Alzheimer's Disease Center and Memory Disorders Clinic,

I have had the pleasure of working for the Memory Disorders Clinic and Alzheimer's Disease Center over the past five years. As of July 21<sup>st</sup> I will be leaving to begin a new position with the US Department of Health and Human Services' Centers for Medicare and Medicaid Services in Washington DC. While this was a difficult decision to make I was offered a special opportunity that I simply could not refuse.

My time at the Alzheimer's Disease Center has been a wonderful experience. I will take with me so many fond memories of the families and patients I have had the pleasure to meet during my work here. I can vividly remember the person that graciously participated in the first of many interviews I conducted for Dr.

Karlawish as well as the time I did the Polka with a patient in the hallway at the Ralston House. The strength, dignity and love I witnessed in the Memory Disorders Clinic will remain with me always.

As I reflect on the past five years I feel quite proud of all that we have accomplished with your help. We have had our first conference for families and people in the earliest stages of dementia; developed a formal feedback mechanism for the reporting of study results to those who participate in research; improved and expanded our website; and published a quarterly news magazine. Thank you all for sharing your thoughts and experiences with me.

I will dearly miss all the patients, families and community members who I have met and with whom I have worked. You will always remain in my heart and mind.

Best wishes,

*Jennifer*

Jennifer Klocinski, MA  
Associate Director, Education and Information Transfer Core  
Editor, ADC Quarterly



# Dialogue On Being Young Adult Carers

by Maggie Harris Longacre & N. Tanya Nagahawatte

This article is a dialogue between two young adults who each have a parent diagnosed with early-onset dementia. Both of us were in our early twenties when our fathers were diagnosed with dementia. Over the past several months we have been communicating through e-mail to share our experiences as young adults in this unusual situation. In our correspondence we have been able to communicate how the experience of dementia has influenced a formative period of our lives.

**Hi Maggie-**

**I was surprised to meet you at your father's Memory Clinic appointment. I estimated that you were in your twenties, like me, and immediately wanted to know about your experience with your father and his illness. I appreciate your willingness to discuss these issues with me. To be quite honest, I had been so preoccupied with the poverty of information about my father's diagnosis that I hadn't really thought about my position in the equation. After months of teetering between diagnoses, thinking critically of my personal situation was pretty far from my mind until I saw you.**

**Thanks Maggie. I look forward to hearing back from you.**

**-Tanya**

Hi Tanya

I absolutely agree with you about your sense of surprise to meet another young adult with a parent diagnosed with dementia. I have to admit, I don't think that I have consciously thought about the fact that, up until now, the only other young adults I have been able to associate with in regards to dementia have been my two older sisters! I appreciate your willingness to share your experience with me for many reasons, but mostly because I became aware of another young adult outside my family that is experiencing a parent's dementia.

How did your family's experience begin? I look forward to hearing from you,

Maggie

**Hi Maggie-**

**My father was in his early fifties and I was in my last year of college when the problems with his memory and thinking began to affect his work and personal life. When I came home to visit my parents, I noticed that he was withdrawn and no longer interested in talking to me. We had enjoyed a close relationship up until that point and the change was distressing.**

**My mother thought that he was under a lot of stress. She had been slowly getting more and more involved**

**in his work, taking over tasks when he started to falter. I think her vision was somewhat blurred because she was involved in the day-to-day aspects of his life. With some distance, I could see the dramatic changes that had taken place. It got to the point that a coworker advised him to get a cognitive evaluation. The results of the evaluation indicated that he was fine, maybe slightly depressed.**

**My mother and I started talking on the phone quite frequently. She was nervous about what was happening and I felt I couldn't add any insecurity to the situation. I tried to be calm and reasonable. It was a difficult negotiation, searching for answers and feeling confused myself while trying to be a voice of reason for my family. I did a lot of growing up in the year it took to secure his diagnosis of probable AD.**

**I would love to hear about your initial experience with the changes your father was going through.**

**Take care,**

**-T**

Hi Tanya,

We have some similarities, but also some differences. I was in college in North Carolina when my father's symptoms began (my parents were in Pennsylvania). I was just beginning my junior year. My father was fifty-seven years old and working full-time for a university as the director of their computing center. This did not seem like the typical time-point in life for either of us to begin thinking about dementia.

Receiving a diagnosis was a long, frustrating process. Our experience seems similar to your family's experience because of signs of depression and uncertainty regarding the exact form of dementia. It took two years to receive a diagnosis of dementia (first believed to be of the Alzheimer's type), and, since then, the exact cause of his dementia remains uncertain.

In the beginning stages of my father's disease I recall being very concerned; however, in my case, my mother tried to protect my two older sisters and I from being too overwhelmed by the situation. She didn't want our choices about careers, marriage... to be influenced by our father's illness.

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# Young Adult Carers...

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She wanted us to make decisions that were in our best interest for our futures. I appreciated this mentality and the freedom to make my own choice, but at the same time the thought of my dad going through such uncertainty was very difficult for me to accept.

So for me, as a young adult, I felt in the middle of wanting to be involved, but at the same time not being ready to be involved because of the uncertainty of his symptoms, but also because of my own future decisions. An interesting place to be during my last years of college :-)

I am sure you have had to make some difficult decisions, at an early point in life, about your involvement in your father's care. Before I go on, what were some big decisions that you had to make, and continue to make, in light of your father's diagnosis?

Hope to hear from you soon. Take care,

Maggie

**Hi Maggie-**

**It sounds like we were both trying to make monumental decisions about our lives when our fathers became ill. I moved to Philadelphia so that I could live close to my family. I was preoccupied with understanding my father's illness. In my research, I found out about the Memory Disorders Clinic at Penn. I met with Chris Clark, the director of the clinic, to find out if I could volunteer at the clinic. Two months later, I started working here full-time.**

**I am not sure how a neurodegenerative illness can't influence the decisions of family members. My father's illness has profoundly affected the decisions I have made in my life. Perhaps because of my youth, I reacted strongly to my father's diagnosis. And, lacking the tethers of traditional adulthood (i.e. mortgages, children, pets) I followed my heart and found a job that satisfied me intellectually and personally.**

**In any case, I feel that all of my work at the clinic and the time I spend with my mother and father is never enough. I am constantly reminded of the limitations of everything that I do. I believe, however, that there is substance and worth in every action and that studying an incurable disease is something that has to be done. So I have taken a tiny slice of that responsibility, in part, because I can.**

**Please let me know how your father's illness shaped your life decisions and what you identify as the unique**

**aspects of being a young adult whose parent has a dementing illness.**

**Thanks a lot Maggie. I don't write or talk about it with many people.**

**Take care,**

**-Tanya**

Hi Tanya,

Thank you for your last email – I could really associate with much of what you wrote. Being at college put me nine hours away from my parents during the early stages of my father's disease. This distance made it difficult for me to come home. In addition, I was on the tennis team at Wake Forest and we had a very competitive schedule. So along with the challenge of academics, I was balancing athletic pursuits. And during the summer I was traveling to compete in tennis events. I wasn't home much but I would speak to my father on the phone or occasionally send him an email – but his declining health was not easy for either of us to talk about.

Following college, I was coming to terms emotionally with the diagnosis of dementia for my father, but I was also thinking about the possibility of playing professional tennis – which would mean constant travel. With the urging of my family, friends, and coaches, I did pursue this route for a short while, but it was difficult in the midst of understanding dementia. I competed in some tournaments, but because of my awareness of my father's condition and feeling that I wanted to be involved - along with injuries and my desire to pursue other interests – I decided I had to travel a new path.

When I wasn't traveling to tournaments, I was living at home while my two older sisters had moved out of the house but were also very involved – be it a visit or telephone call. A year later I got married and moved out of the house but chose to stay local.

There are times when I think about my decision to stay close in proximity to my parents. This decision certainly had a lot to do with my father's health, but not everything to do with it. I strongly believe in community and family care, but I also believe in choice. I believe that a good caregiver, at any stage in life, is never going to be the one that feels obligated to provide care – and no two situations are ever exactly alike.

Like you, I thought about work that was related to health. But, at that point, I could not comprehend working within the dementia field – I was already too saturated. I decided to combine my interest in psychology and health (physical activity). I took a job in health psychology research and began a graduate program in health education/public health.

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## Young Adult Carers...

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All of this was coupled with helping to provide care for my father when I could. It definitely felt exhausting at times.

I am now more interested in topics of caregiving and health policy in relation to dementia. I think this has a lot to do with the fact that I am not as consumed by being part of a caregiving team. I am now 28 years old and my father has been living in a long-term care facility for over a year (after 7 years of family in-home care). Although I visit him regularly, it is a different level of attentiveness (but certainly not a different level of coping).

In sum, deciding where to live and what professional career to pursue has undoubtedly been influenced by my experience with my father's disease. I agree completely with your statement: "I am not sure how a neurodegenerative illness can't influence the decisions of family members." I would add, however, that how young adults are influenced is largely unknown. I do think we agree that taking an interest in family and the condition of health and well-being has only helped to build us up – although, certainly, the hard way.

-Maggie

***In the next Quarterly, our correspondence will focus on the decisions that we have had to make in regards to immediate and future needs in the presence of a parent's diagnosis. This correspondence is also available on the Alzheimer's Disease Center web site at <http://www.uphs.upenn.edu/ADC/>.***

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## Voting... continued from page 1

ing voting assistance to residents? What are the political and ethical consequences of voting by persons who lack the capacity to vote?

These questions are important not only to family members who live with and care for a person with dementia, but also long-term care professionals who are required by law to assure their residents' ability to exercise their civil rights, including the right to vote.

The events that occurred during the 2000 presidential election in the state of Florida suggest that in some cases this problem is not trivial and could plausibly impact on the outcome of an election. Twenty percent of voters in the 2000 U.S. elections were persons over 65 and age is one of the principal risk factors for developing dementia<sup>1,2</sup>. There are an estimated 4

million persons in the United States with dementia, and there will be an estimated 20 million by 2050<sup>3,4</sup>. As the number of persons with dementia increases, the scope of this issue will only increase.

To address the questions raised when persons with dementia vote, the Greenwall Foundation has funded a working group of experts from the disciplines including law, ethics, government, neurology, geriatrics, and psychiatry. The goal of this working group is to identify and address the legal, ethical, constitutional, political, medical, and practical issues regarding the rights and abilities of individuals with dementia to vote. This panel of experts will work to define the dimensions of the issue and develop consensus guidelines for policy and for future research.

The panel will meet for three 1 ½-day-long meetings over 18 months. The first meeting will be in August. The project team leaders are Doctors Jason Karlawish M.D., David Drachman M.D., and Paul Appelbaum M.D. Dr. Karlawish is an assistant professor of medicine at the University of Pennsylvania whose scholarship focuses on the ethics of research and care that involves people with dementia. Dr. Drachman is emeritus chair of the Department of Neurology at the University of Massachusetts and his scholarship focuses on diagnosis, treatment and public policy for persons with dementia. Dr. Applebaum is Chair of the Department of Psychiatry at the University of Massachusetts and his research focuses on issues in law, ethics, and psychiatry. The rest of the panelists are listed in the figure on page 6.

The products of this working group will be a set of papers, guidelines, and educational materials. The experts will produce papers addressing issues relevant to their disciplines to be published in appropriate journals. All of the panelists will be co-authors of a summary paper containing all guidelines, recommendations, and proposals for research. The working group will also lead to the creation of educational materials for families and clinicians, such as a brochure that summarizes ways to assess a person's capacity to vote. The publications will be disseminated to relevant groups, opinion leaders, and policy makers such as state attorney generals, the American Medical Association, the American Geriatrics Society,

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# Remaking of the self: "The Story of My Father: A Memoir."

Book review by Jason Karlawish, M.D.

On a sunny Saturday morning in June, Sue Miller awoke to a phone call from the police. They had her father in custody, but there was no crime. He was found wandering the streets, lost in his solo journey to his house in New Hampshire. Five years later, when he lived in "level four" of Sutton House, he asked his daughter Sue to dictate a letter to his daughter Sue. "Dear Sue," he said to his perplexed daughter, "I am writing to the one we know as Sue. To be in touch...." This is the story of a daughter who is a novelist and once upon a time was the caregiver for her father who had Alzheimers Disease.

A novelist who takes up the story of her father's Alzheimers Disease is an excellent experiment to better map the borders of territories we are still discovering: between what we know is true versus what we can only believe is true, between the acts that are the acts of the person and those that are the symptoms of the disease.

This story is doubly poignant because the person with the disease, her Father, was a historian: a discipline whose concern is with reconstructing the facts of an event so that they tell the true story, and tortured by the fact that some facts are forgotten. Some are even lies.

Miller lets the narrative of her father and mother and their lives together weave a story of memory. Memory loss in Alzheimers Disease is tragic, but just as tragic is the way our own minds and lives conspire to forget. Miller reflects how when she turned sixteen and left for college, long before her Father's illness began, "he vanished from my life suddenly – I can't find him in memory in any sustained way for twenty years or so. I simply stopped knowing him in any real sense." Why did this happen? Because, she reflects, her mother was the one who answered their correspondence. This was a family that actually wrote letters. The more common equivalent is the father who routinely hands the phone over to mother.

This story is a test of her ability to construct and reconstruct events and live and histories. It causes

her discomfort not because the way she recalls her father may not be how others recalled him, or even that some of her "facts" are wrong. Her discomfort is far more existential because it is with memory: its variable nature and its role in her family.

Why do we care so much about the loss of memory? Once upon a time, we devoted our lives to the discovery of the divine. The overarching mission of science, literature and philosophy was to better understand the divine order. Our culture retains residua of this. Some religious strive for a cloistered life. But now, we are in the age of the self. The mission of science, literature and philosophy — and the more contemporary enter-

tainment industry — is self-discovery and then improvement of that discovered self. Among the many testaments of this age is the confessional autobiography. We are drawn not into the lives of people who rose to greatness so that we too may be great, but into the story of tortured

*The Story of My Father: A Memoir.* by Sue Miller. 2003. Knopf Group. 192 pp. \$22.50

On sale at [Alibris.com](http://Alibris.com), [Amazon.com](http://Amazon.com), and [BarnesandNoble.com](http://BarnesandNoble.com)

lives. We don't read about Napoleon but a young woman's life on Prozac.

No wonder then that Alzheimers Disease is the disease we most dread. For unlike other chronic diseases that rob the body of glamour, strength and endurance, Alzheimers Disease and other dementias have the single distinction of robbing the self of its very self. It is no accident that in this age of the self, there are books about Alzheimers Disease.

When her father asks her to dictate a letter to his daughter Sue – "I need to be in touch with Sue" – she reflects how he is saying that the person he sees before him in his room at the assisted living facility and the memory of the person who is his daughter had diverged. Why? Because she had become another Sue – a nice woman who makes decisions for him, helps him with some of his daily tasks, talks to the doctors and nurses about him, offers him anodyne stories rather than candid answers. In a word, she had transformed from his daughter and into his caregiver.

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# Book Review...

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Witnessing her father’s dementia progress offers a reflection on the substance of the self. As the brain degenerates, skills are lost and behaviors change. A friend remarks to her that her father’s belligerent behavior reveals a kind of primordial self that the decay of the “higher brain” unleashes. But Miller sees the interpretation as just that: mere interpretation of signs and symptoms. And yet the question is posed: at what point in the decay of the self, does it cease to be the self? Does it peel away until an inner core remains, such that the things that remain are the more well formed, or true, parts of the self? Or does it shatter like a china piece dropped again and again into smaller bits? Some parts are broken into unrecognizable bits while others remain recognizable. Miller realizes that she can pose these questions long before her father received his diagnostic label. Was this quiet reticent man in fact showing the earliest signs of dementia when his wife insisted that he for once, just once, remember what attracted him to her in the first place? At what point did the behavior of the self transform into the symptoms of the disease?

This is not simply a story of the usual diagnostic uncertainties and clinical indignities. The single chapter that attempts to sum up key points of the science distracts and can easily be skipped. Miller’s story tells how we only know our selves because of others’ selves. Perhaps the redemption of Alzheimers Disease is just this knowing: it takes a disease to rob the one’s we love of their selves in order to realize that our selves are not ours alone, but are made from the matrix of selves around us.

The implications of this – political, ethical and economic – resonate far beyond the particulars of this well written case study. The last election was about soccer moms – over worked women who hauled a team of their and other women’s children to safe suburban playing fields in mini-vans. What politician will have the insight to make the next election the election of the caregiver?

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 ● **New drug for Alzheimer’s disease pending approval by the FDA** – Memantine: What is it? How does it work? Visit our website (<http://www.uphs.upenn.edu/ADC>) for an article by Dr. Jason Karlawish on this potential new therapy.  
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and the American Bar Association. Finally, this working group will identify topics in need of further research.

**Panelists**

**Legal experts:**  
 Richard Bonnie, J.D., University of Virginia  
 Pamela S. Karlan, J.D., Stanford  
 Charles Sabatino, J.D., American Bar Association

**Government and Voting Policy expert:**  
 Christopher Patusky, J.D., University of Pennsylvania

**Ethics and Long Term Care experts:**  
 Rosalie A. Kane, Ph.D. University of Minnesota  
 Thomas Lawrence, M.D. University of Pennsylvania  
 Kenneth F. Schaffner, M.D., Ph.D. George Washington University  
 Harry Moody, Ph.D. Brookdale Center on Aging

**Dementia experts:**  
 Constantine Lyketsos, M.D. Johns Hopkins University  
 David Knopman, M.D. Mayo Clinic

As the 2004 U.S. Presidential election approaches, the products of this working group will be especially useful to affect policy and provide guidelines. Support for this project is provided by a grant from the Greenwall Foundation, which makes philanthropic grants to support work in bioethics and the arts & humanities. For more information about the project, please contact Jason Karlawish, MD at [jasonkar@mail.med.upenn.edu](mailto:jasonkar@mail.med.upenn.edu) or 215-898-8997.

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# Collaborations with the Delaware Valley Chapter of the Alzheimer's Association

## **Alzheimer's Disease Center awarded Bach Fund award for West Philadelphia Dementia Education and Wandering Prevention Program**

Wandering is a serious and potentially life threatening symptom of Alzheimer's disease and related dementias. This is a common problem. It is estimated the 60% of patients will wander at some point during their illness. The national Safe Return Program offered by the Alzheimer's Association provides assistance in finding someone who has become lost and provides identification products (e.g. ID bracelet and clothing tags) for participants. However, this program has been underutilized in the West Philadelphia neighborhoods.

To ameliorate this problem the ADC has developed a dementia education and wandering prevention program, which has been funded by Presbyterian Medical Center's Bach Fund. As part of this program The University of Pennsylvania's Alzheimer's Disease Center and the Delaware Valley Chapter of the Alzheimer's Association will be holding Safe Return registration drives in the West Philadelphia community throughout the year. The Bach Fund grant will provide 50% scholarships for the one time registration fee reducing the cost from \$40 to only \$20. During registration drives volunteers will be available to assist with the application process. Many of the registration drives will be held in conjunction with the Alzheimer's Association's Memory Screening Project (see news item below).

## **Alzheimer's Disease Center in partnership with Delaware Valley Chapter of the Alzheimer's Association's Administration on Aging grant: Memory Screening Project**

The Delaware Valley and Greater Pennsylvania Chapters of the Alzheimer's Association have been awarded an Administration on Aging's Alzheimer's Disease Grant to implement the Pennsylvania Memory Loss Screening Demonstration Project. This three-year project will serve two populations in Southeastern Pennsylvania, individuals with early-onset dementia and people living in the African-American, Latino and Asian communities.

An important component of the project will be memory loss screening events to be held at community sites

throughout Southeastern Pennsylvania. During these events individuals can receive a brief memory loss screen and referrals to healthcare providers and community services for those identified as having possible memory loss.

The University of Pennsylvania's Alzheimer's Disease Center is a key partner for this project, providing technical training to the Association and it's volunteers. The ADC advised the Alzheimer's Association in its selection of appropriate screening tools and trained volunteers in how to conduct the memory loss screen-ings.

## Staff Awards and Honors:

**Jason Karlawish, MD has received the 2003 American Geriatrics Society, Best Paper Award for Outstanding Excellence in Geriatrics Research (ethics category).** Dr. Karlawish presented his paper "Can people with Alzheimers disease make a decision about treating Alzheimers disease?", co-authored with Bryan James, MBioethics; David Casarett, MD; and Pamela Sankar, PhD at the annual AGS meeting. The paper reports the results of an instrument that measures the ability of a person with Alzheimer's disease to make an AD treatment decision.

**Mark Forman, MD PhD, Research Associate at the Center for Neurodegenerative Disease Research has received the American Society for Investigative Pathology's (ASIP) Experimental Pathologist-in-Training award for 2003.** The proteins tau and á-synuclein are essential to normal brain function but when they aggregate become toxic. The protein tau is the main component of the "tangles" seen in a variety of illnesses including AD while Lewy Bodies which are the hallmark of Parkinson's disease consist of the protein á-synuclein. Dr. Forman's research focuses on understanding these proteins and how they develop into their toxic forms.

**Alzheimer's Association's 2003 Statewide Education Conference to be held November 19, 2003.**

*Featuring Dr. Peter V. Rabins, author of "The 36 Hour Day"*

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Dover, Delaware

To receive a registration brochure contact Claire Day at  
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# ADC QUARTERLY



"Dedicated to improving the health, well-being and quality of life of patients  
and their families."

## Research Opportunities

**Can a measure of brain waves detect Alzheimer's disease?** This study examines whether measuring brain waves that are created when a person listens to specific sounds can detect Alzheimer's disease. The brain waves are recorded by an EEG, electroencephalogram. Participants undergo two EEG sessions each lasting about 2 hours.

**How is the stress hormone cortisol related to a genetic risk factor for AD?** This study looks at the relationship between the gene APOE and levels of cortisol in the blood, urine and spinal fluid.

**Two drug studies open for enrollment:** a Statin and dietary supplements (folate and two B vitamins) are being tested for their ability to slow the progression of AD. To learn more about studies at the Alzheimer's Disease Center contact Kris Gravanda, study coordinator, at 215.349.5903 or email her at krisg@mail.med.upenn.edu.

## Philadelphian's go to Washington

On April 1st forty-eight people from Philadelphia and the surrounding region traveled to Washington, DC to attend the National Alzheimer's Association's Annual Public Policy Forum. As part of this advocacy effort, Mr. Donald Kurtz and his partner Roz Ruby testified during the Senate Hearing hosted by Senators Arlen Specter, PA/R and Tom Harkin, IA/D. Mr. Kurtz was able to raise awareness and capture the attention of the hearing attendees by telling of his experience living with early-onset Alzheimer's disease.

Mr. Kurtz and Ms. Ruby shared their experiences not only because of their concern with the suffering of those currently affected by AD and their families but due to the fact that without a cure as many as 50% of the those in the Baby Boom generation will develop a dementing illness bringing significant social and financial challenges to Western nations.

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