

# Salon Report

## Alzheimer's in an Aging Society

A discussion hosted by:  
The International Longevity Center-USA and  
Columbia University  
Mailman School of Public Health



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# Introduction

Alzheimer's disease is a looming epidemic that places a tremendous health and financial burden on both developed and developing countries. The "graying" of the world's population is contributing to its rapidly increasing prevalence, with 35.6 million people worldwide expected to be living with Alzheimer's disease and other dementias in 2010, 65.7 million in 2030, and 115.4 in 2050.<sup>1</sup>

Scientific research conducted during the last two decades has greatly advanced our understanding of the mechanisms of the disease, and has led to improved diagnostic tools such as neuroimaging techniques, biomarker identification, and cognitive testing. Yet these advances so far have not translated into therapeutic targets validated by the scientific community.

Governments have allocated resources for Alzheimer's disease, but not nearly enough to conduct large-scale studies on drugs that could potentially alter the course of the disease. And unlike other diseases such as cancer and cardiovascular disease, Alzheimer's does not have substantial private funding from foundations or associations.

In the meantime, society faces the dual challenge of investing in long-term treatment solutions, while simultaneously addressing the immediate health, financial, and social needs of millions of people who already are living with Alzheimer's disease and their caregivers.

Perhaps most staggering is that despite the alarming statistics and serious impacts of the disease, Alzheimer's is not a priority in the public mind. It is riddled with misperceptions, doesn't touch people's hearts, or have a "face."

What is lacking is a collaborative movement—a unified, global voice representing all those with a stake in Alzheimer's disease and dementia research, care, and advocacy—to raise public awareness of the disease and its societal burden, put Alzheimer's on the agenda for governments and world organizations, and raise appropriate funds for research and care.

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<sup>1</sup> Alzheimer's Disease International. World Alzheimer Report 2009.

# The Conversation Begins

A distinguished multidisciplinary group of experts in medicine, policy, economics, psychosocial science, and patient advocacy related to Alzheimer's disease met at the Mailman School of Public Health in New York on September 22 to begin the collaborative process.

A wide range of topics were discussed including generating global disease awareness, building patient education and support networks in Europe, recognizing needs in developing countries, and creating incentives for conducting clinical trials on next-generation treatments.

Following are the key needs identified during the dinner salon.

**Lack of awareness among consumers and physicians necessitates education campaigns, global endorsement**

In a world filled with basic problems such as children lacking filtered water and mothers dying from childbirth, dementia ranks low on the global awareness scale. Not only are consumers unaware of its looming threat, but experienced professionals who oftentimes encounter the Alzheimer's patient are not sufficiently knowledgeable about the disease, its course and manifestations. Even more surprising is the large number of general practitioners in developed and developing countries who are not trained to make a proper diagnosis, and mistakenly attribute any signs of dementia to the natural course of old age. What is needed are consumer education campaigns, as well as physician education, especially at the primary care level, to ensure that people with signs of the disease are diagnosed early and treated with current therapies that aim to preserve quality of life. At the same time, endorsement by a global health authority such as WHO is needed to generate awareness from national governments, especially those in the developing world.

**Importance of early detection in preventing disease onset**

With overwhelming evidence that the pathologies of Alzheimer's disease can start 20 or 30 years before symptoms appear, there is a critical need for accelerating early detection as a means of disease-onset prevention. In the U.S., Europe, Japan, and Australia, compelling work in biomarkers, neuroimaging, and cognitive testing is being conducted, but these advances have yet to be translated into effective preventive therapies. Barriers include poor government funding; lack of infrastructure for conducting large-scale studies of people asymptomatic with Alzheimer's; and a regulatory climate requiring a candidate to be studied for 15-20 years (about the time the patent runs out). However, with proper incentive, long-term prevention trials could be conducted on treatments that aim to change the course of the disease.

Need for scientific consensus on biomarkers of early disease to identify patients for clinical trials  
Hand in hand with improved early detection is the need for scientific consensus around a definition of early disease (based on a set of validated biomarkers), which would identify the critical population for clinical trials on emerging Alzheimer's disease therapies. It is believed that the identification of established targets for Alzheimer's disease would unleash a tremendous amount of resources from the private sector to develop the next generation of therapies that would prevent symptom onset.

Dual challenge of preventing disease onset in long term while preventing disability in short term  
The rapidly increasing prevalence of dementia requires a long-term plan of developing treatments and preventing disease onset. But at the same time, millions of people around the world currently living with dementia require immediate care systems to improve quality of life and prevent disability. The challenge therefore becomes how to simultaneously remain focused on the needs of both society and the individual. This will require a recognition that one goal doesn't supplant the other—that caregivers can implement a variety of cost-effective interventions today as researchers find ways to prevent new cases of Alzheimer's disease from arising in the future.

Importance of caregiver interventions, and learning from caregivers and family

In attending to the immediate needs of dementia, the focus needs to be on caring for the patient who is suffering from a neurological disability, as well as the caregiver who is at risk of depression or physical health problems. It is well documented that behavioral therapies or types of stimulation such as art or music therapy—which are not costly—can enhance a patient's quality of life. Likewise, there are a number of caregiver interventions that provide psychological and social support. There is much to be learned from those on the frontlines—families, friends, caregivers, and the community—who can relay from a practical standpoint what works and what doesn't, what's needed and what's useless.

Need for accurate epidemiology to project current and future needs and argue credibly for funding  
Alzheimer's disease typically does not appear on the political radar until the conversation focuses on the disease's cost to Medicare or Medicaid (in the U.S.) and other countries' health systems. But a rigorous analysis of the economic burden of illness of Alzheimer's disease has yet to be conducted. Part of the reason is because there are few and unreliable Alzheimer's prevalence figures. To have a compelling business case, a first step would be to have accurate epidemiology.

To argue credibly for funding, one approach would be to demonstrate that the investment needed for Alzheimer's disease is trivial compared to the expected costs to governments around the world. Take, for example, the burden in the United States. If next year, Alzheimer's will cost Medicare and Medicaid \$184 billion and spending is \$400 million at NIH to avoid that cost, the cost-savings case has been made. In this way, the investment that needs to be made is measured by how much cost will be

avoided in the future. It must be noted, however, that governments have traditionally been focused on spending rather than saving.

#### Putting patients forward: Learning from AIDS advocacy and fundraising

Alzheimer's disease is in desperate need of good marketing—it needs a “face.” In the United States, at least, there is no image that tears at people's hearts, or consistent message that generates a positive reaction from Washington, D.C. The challenge has been, “what to do with a population that can't speak for itself?” It's time to take a page from the AIDS movement, which has been able to elicit compassion and a tremendous amount of research money from governments and private foundations by putting forward the AIDS patient. Physicians and experts alone cannot convince the public about the consequences of this devastating disease. But it can be extremely powerful if patients with clinically diagnosed early Alzheimer's disease, who can speak for themselves, or their families, publicly tell their stories about how they are, and will be, affected by the disease.

#### Harnessing the power of the Internet as a social networking and mobilizing tool

Unlike government communications or corporate advertising, the Internet enables a massive number of people to connect on an issue very quickly. Internet-based social networking tools can be easily developed with relatively small private investments, and be used as a forum for connecting anyone affected by Alzheimer's disease, exchanging good practices, and posting newsworthy information. In a short period of time, it would be possible to learn, for example, about interventions that improve quality of life, generate the much needed disease awareness, and even get people mobilized on a political or financial level.

#### Understanding risk factors and lifestyle choices that can contribute to Alzheimer's disease

Although there is accumulating evidence that cardiovascular disease, hypertension, diabetes, and vascular factors constitute a risk for Alzheimer's disease—and that modifying such disease risks through exercise, weight loss, and glucose monitoring can have preventive benefits relevant to dementia—the link needs to be better understood and publicized. People could not only avoid risks as early as in childhood, but those with diabetes and heart disease may be more compliant with their treatments if they knew they were at risk for dementia. And although caution must be exercised in characterizing Alzheimer's as a lifestyle disease, data are showing that the living environment may have an impact on learning and memory function, necessitating additional studies on interventions that are specific to Alzheimer's disease.

#### Learning from successful initiatives in France, UK, and Japan to make AD a priority

France/Europe: One year ago, it was part of France's national plan to make Alzheimer's disease not only a French priority but also a European priority. Today, there's a European initiative with four priority actions: 1) promote early diagnosis (there are a large number of general practitioners,

especially in France, who are not focused on the importance of early diagnosis), 2) conduct epidemiology studies because there are few reliable figures on number of patients, 3) promote exchange of good practices (already convened 10 European experts to discuss ways of caring for patients at home vs. institutions), and 4) exchange ethical practices (a project led by Germany project is producing case studies on practical issues such as, “what if my patient refuses to eat,” based on opinions from various European experts). Additionally, making Alzheimer’s disease a priority has led to the development of a new research tool in Europe called joint programming, in which 20 countries have voluntarily decided to work together and contribute funds under a single objective of combating Alzheimer’s disease.

UK: Once the UK was able to show that dementia was costing £17 billion and expected to cost £50 billion, and that it was costing more than cancer, heart disease, and stroke combined, health departments, social care departments, and finance departments acknowledged the strategic priority for dementia. In addition, through compelling stories from caregivers and researchers about the possibility to live well with dementia, the media was instrumental in depicting stories of hope and helping to de-stigmatize the disease.

Japan: Since 2005, Japan has been focused on enlightening citizens about dementia through a 10-year awareness campaign. Its goals are to train citizens to support the dementia community and establish a network of families, dementia sufferers, professionals, caregivers, local organizations to create the infrastructure needed to support people with dementia. There are already 1 million citizen supporters. Japan also has been dedicated to elevating the importance of the caregiver because social recognition of caregivers is very low. The government has provided specialized training to 1,200 leading care workers so far, who in turn have trained 120,000 care givers in their respective communities—essentially building a professional dementia caregiver society.



Recognizing needs of developing countries to combat Alzheimer's disease as the population ages  
By 2050, 72 percent of people with Alzheimer's disease will be living in the developing world, so it's important to recognize the challenges these countries will face. How will patients effectively be treated at home since there are no long-term facilities. How will they be diagnosed early when primary care physicians still don't know signs of dementia? How can awareness be generated through the Internet when people don't have access to computers, let alone the Internet? Developing countries, in particular, would benefit tremendously from higher health authorities recognizing the disease—this would send a message to all governments. Similarly, developed countries can learn from poorer countries with more limited resources.

#### Overcoming regulatory and cost barriers to new treatments

Although research is proceeding, with monoclonal antibodies, vaccines, histamine antagonists and phosphodiesterase inhibitors in the pipeline, a void remains in the regulatory process. Specifically, there needs to be someone working with international regulatory authorities to speed the development and assessment of these new compounds—to allow for a Phase two study, or register a compelling molecule with one Phase three trial, or not be required to do a head-to-head trial to receive European approval, for example.



# Solutions

It will take one voice—one collaborative movement with one consistent message—to address the issues facing Alzheimer’s disease and make it a global priority. The collaboration must comprise a cross-functional, multidisciplinary group of professional experts, non-profit organizations, private companies, and representation from developed and developing countries. There should be a strong, trusted convener, a focused mission with annual goals, and powerful spokespeople with compelling stories. And to make this a sustainable movement, it must be durable, yet flexible enough to invite new experts or organizations. Done right, this collaboration has the ability to generate scientific advancements, public and private funding, political recognition, media attention, advocacy mobilization, and public awareness.

The following items have been recognized as priorities for the international collaborative movement:

- Create more awareness of, and conduct more research on, how to provide better interventions for the people who are already living with dementia.
- Educate public that Alzheimer’s disease is not an inevitable part of growing older, but a separable disease.
- Improve early diagnose by conducting regular cognitive function testing for everybody over 50 years of age.
- Create better health metrics to allow for a comparison of the burdens of different disease and mortalities to indicate where we are under-investing.
- Increase research in social sciences.
- Use international platforms like G20 and Davos to advance the collaborative Alzheimer’s agenda.
- Simplify regulatory guidelines to approve incremental innovations.
- Create a Global Fund for Alzheimer’s disease.
- Engage young people in generating public awareness.
- Develop clear, simple messages that are consistently communicated.
- Create public awareness campaigns.
- Call for investments in high-risk basic research into multiple innovative pathways, which may, or may not yield biological, psychological, or social interventions.
- Use the AIDS movement and other successful advocacy movements as a model for raising public awareness, increasing funding, and building a political platform.
- Recruit more scientists to the field.
- Encourage large private foundations to become interested.

Now is the moment to put Alzheimer's disease on the global agenda. If not, in twenty years, there will be upwards of 65 million people who will not be able to care for themselves; will be a physical, emotional, and financial burden to their friends, families, and society; and wreak havoc on global health systems. Establishing an international collaborative movement is the first crucial step in helping to conceptualize a world free from Alzheimer's disease.