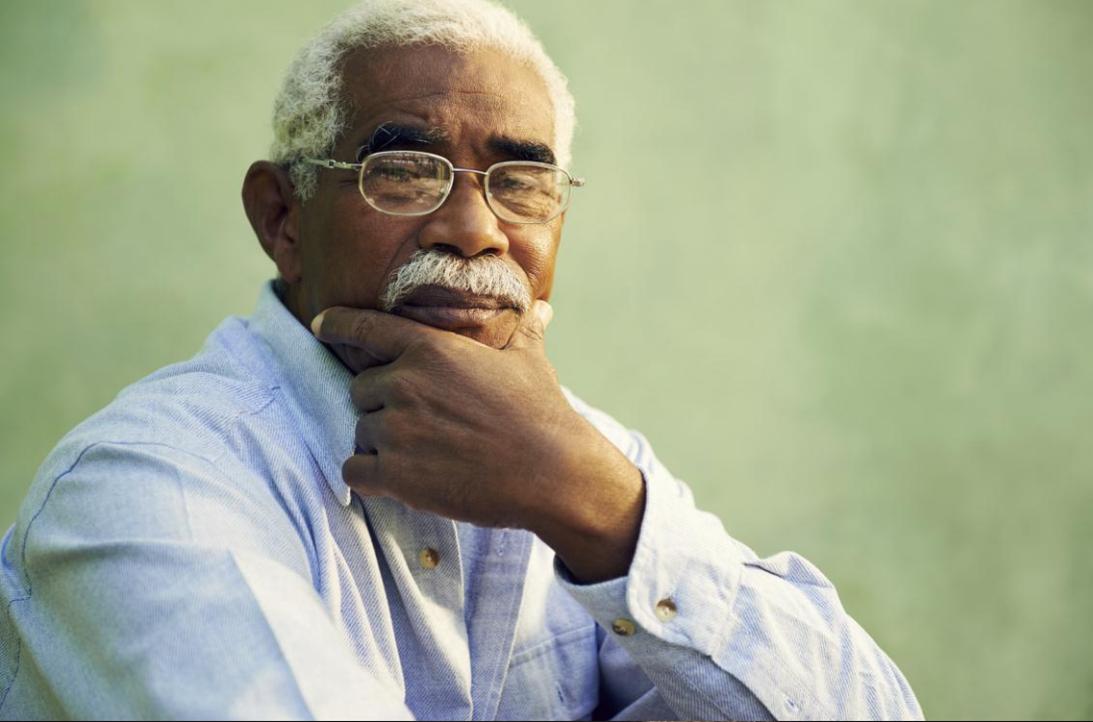


Follow up of 2013 G8 commitments

The journey so far, and where
next?

Dr Dennis Gillings, CBE
World Dementia Envoy

Dementia in Europe: a challenge for our common future



In 2013, an estimated **44.4 million people were living with dementia globally.**

By 2050, that will reach **135 million people.**

Cost of dementia care globally is **\$604 billion per year**, that's **1% of global GDP.**

The image features the BBC News logo centered on a background of white, fluffy clouds. The logo consists of a dark red square containing the letters 'BBC' in white, bold, sans-serif font, stacked above the word 'NEWS' in a larger, white, bold, sans-serif font.

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World Dementia Council





MANY ALZHEIMER'S CASES 'AVOIDABLE'

By PRESS ASSOCIATION

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A third of Alzheimer's cases are potentially preventable if people improve their lifestyles, according to a new study.

Factors including a lack of exercise, smoking and a lack of education can all contribute to the disease, and reducing the risk from these could prevent some nine million cases by 2050, the research published in *The Lancet Neurology* today suggests.

The latest study, led by Professor Carol Brayne from the Cambridge Institute of Public Health at the University of Cambridge and funded by the National Institute for Health Research, lowers the estimate from previous research in 2011 which had suggested as many as one in two cases are preventable.

The seven risk factors associated with Alzheimer's are diabetes, midlife hypertension, midlife obesity, physical inactivity, depression, smoking, and low educational attainment.

It is thought that by 2050 more than 106 million people will have Alzheimer's, up from 30 million sufferers in 2010.

Dr Deborah Barnes from the University of California, San Francisco and the San Francisco VA Medical Centre, who led the 2011 study and is a co-author on the new study, said the latest information could help to prevent and manage the disease in the future.

"It's important that we have as accurate an estimate of the projected prevalence of Alzheimer's as possible, as well as accurate estimates of the potential impact of lifestyle changes at a societal level," said Dr Barnes.







World Dementia Envoy speech
Follow up of the 2013 G8 Commitments:
The journey so far, and where next?
**Italian event, Dementia in Europe: A Challenge for our
Common Future**

**Follow up of 2013 G8
commitments**

The journey so far, and where
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Dementia in Europe: a challenge for our common future

GREETING & THEME Intro

Good morning and thank you for giving me this opportunity to give an update on the follow-up of the 2013 G8

commitments and the progress of Global Action Against Dementia.

Almost a year ago, health ministers from around the world met for the first ever G8 dementia summit in London, under British leadership. They realized that the exponential rise in dementia poses a threat not only to the social and emotional wellbeing of people around the world, but their economic wellbeing too.

It is projected that the 44 million people living with dementia around the world today will reach around 120 million by 2050. The cost associated with dementia is also set to grow from \$604bn today to over a trillion dollars by 2050.

Without action, these costs will be hugely damaging to economies and societies around the world, as people leave the workforce to care for loved ones and increasing numbers of people live with dementia.

Those ministers meeting last year realized that there needed to be concrete action and an ambitious goal. They set themselves the task of finding a cure or disease-modifying therapy by 2025.

That's a big ask, but working together, it is one I truly believe we can answer.

In order to identify the reasons why there hasn't been enough progress in dementia research, the British Prime Minister, David Cameron, appointed me as the first ever World Dementia Envoy, with a council of experts from around the world to work with me in finding out the problems – and crucially, the what the solutions should be.

Before I set out what these may be, let's just remember the scale of this challenge - and why it is so essential we tackle it head on, and fast.



1 click (for first set of pictures)

These are the faces of Alzheimer's. Most belong to the so-called Silent Generation, the parents of the Baby Boomers. But there are younger faces, too and whatever their generation, they are effectively silenced.

2 click (for second set of pictures)

As the brain's neuronal connections decay, they lose their connections to other people, to their loved ones, and finally, to themselves.

How many of you know someone—colleague, friend, neighbor—who suffers from dementia? Raise your hands. And how many of you have a family member—parent, grandparent—with dementia.

(Dennis' hand is raised) My mother died of the disease last year. She suffered through all the progressive losses of memory and autonomy over a period of 18 years. I am here, most importantly, as the son of Dulcie Gillings, dementia patient. I note a similar situation is true for many of you. We're here because all the mothers, fathers, sisters, brothers, sons and daughters who struggle with this disease cannot fight for themselves.

In 2013, an estimated **44.4 million**
people were living with
dementia globally.

By 2050, that will reach **135 million**
people.

Cost of dementia care globally is **\$604**
billion per year, that's 1% of
global GDP

Click (for muted stats slide)

Rising incidence of dementia in the world's aging population is moving toward us, gathering strength like a tidal wave. You know these figures well but they have to be repeated because their magnitude may well overwhelm society's ability to cope.

1 click

- In 2013, an estimated **44.4 million** people were living with dementia.
- The World Health Organization expects that number to nearly **double every 20 years**.

2 click

- By 2050, there will be 135 million people living with dementia.

With these rising millions, the **economic impact of dementia** is increasing relentlessly.

3 click

- Cost of dementia care around the world is \$604bn each year.
- In the United States, costs are expected to total **\$20 trillion** over the next 40 years. This is extraordinary—

an amount that **far exceeds the entire US national debt** so often decried by politicians.

The UK and the United States are not alone in facing this tidal wave of disease burden. The whole of Western Europe as well as Australasia and Japan are also facing the hard reality today. And during the next 30 years, it will spread to the developing world...

- By 2016, China will surpass the U.S. in total number of patients living with dementia.
- By 2050, as many as two thirds of patients will come from developing nations.

Consider what this means in terms of the world's hard-won progress in healthcare.

During the 20th century, average **life expectancy** in the Western World increased by approximately 30 years, thanks to the victories won through public health, vaccination, and pharmaceutical innovation. We stand to lose much of that gain to the ravages of dementia. This would be a tragedy for medical research and to everything that we, and our colleagues, have devoted our careers to.

We have three lessons from which to learn: Ebola, AIDS and “The War on Cancer”

Ebola is certainly the medical topic of the moment.

Click for Ebola video



This virus has been known for 40 years but the world did not heed the threat. We did not mobilize when we had the

chance—there were few cases in poor countries. Ebola did not register as an investment priority for research, resources, training and emergency plans ready in advance.

Now we face a world health crisis. There are thousands of cases in Africa, with a projected outbreak of one million or more by the end of the year. The first U.S. case appeared this month in Texas and now two healthcare workers treating this patient have tested positive for the disease. Two weeks ago in Spain a nurse treating an Ebola patient also tested positive. Last week, a UN worker died in Germany.

As we race to contain Ebola with quarantine, the pharmaceutical industry is mobilizing with great intensity, in partnership with governments, to introduce a vaccine in the shortest possible time. We know what the incidence of dementia is going to be over the next 40 years. We know what the social and economic impact will be. So, it is important to make intelligent investment now to mitigate what could become a future shock to our social and economic fabric.

AIDS provides a model we must use as an example of the power of advocacy.

The HIV/AIDS epidemic changed the world. The marginalized gay community took to the streets in the

U.S., raging against their society's lack of empathy and action. They demanded more research. They demanded that potential treatments be available NOW. They influenced research priorities, inspired funding, and drove changes at FDA to speed potentially life-saving drugs to patients. They engaged a network of advocates, famous faces who rewrote the book on patient advocacy and achieved revolutionary changes in attitude.

This zeal woke society up to the threat of the devastating epidemic. Perhaps more important, it unleashed a flood of research funding that produced break-through therapies that changed HIV/AIDS from a modern plague into a manageable chronic disease.

This is the zeal we need to bring to the fight against dementia.

Turning to the War on Cancer, it provides a proxy for the challenges and the pathway to conquering a complex chronic disease.

Like cancer, dementia presents us with a disorder so complex that we have barely scratched the surface in our efforts to understand its cause, progression, and targets for intervention.

A half-century of progress in oncology shows us that:

- Breakthroughs will come from insights at the molecular level.
- Like cancer, dementia is many diseases and multiple treatments will probably be needed;
- Progress will be made in small, incremental advances, gathering momentum so that disease subgroups become amenable to treatment and cure over time.

Three barriers to progress on dementia deserve specific mention.

First, education will be vital. There is a huge lack of knowledge about the disease, which even now is often seen as “normal aging” rather than a disease.

Second, the elderly who tend to suffer from dementia are also more isolated from the rest of the population. The fear of dementia is now even greater than the fear of cancer according to attitude surveys. Stigma and stereotypes are recognized obstacles to both quality of care and quality of life. Fear and shame can make patients and family members hide the diagnosis; relationships are

damaged, interaction with people decline. The lack of any substantial progress toward effective treatment only intensifies a sense of hopelessness.

A third barrier is lack of funding. Despite the looming crisis in care costs, dementia receives only about one-tenth of the financial support given cancer.

The scale of investment in neuroscience research is the key to cracking the problem of neuro-degeneration. The goal must be to **identify and test the most promising interventions** as quickly as possible to reduce the burden of disease

This will require **billions of research dollars**. But the size of this investment will be insignificant **compared to the trillions** needed for care in the years ahead. If we find the political will to make this investment now, the returns in public health benefit and savings in future dementia care costs will be enormous.

We have economic models of dementia impact, built by the **London School of Economics**. The data are compelling but may do little to make politicians recognize the urgency for of immediate action.

The funding dilemma in the U.S. illustrates the problem. Dementia must compete with other diseases. While there is interest in increasing funds for dementia research in the U.S. Congress, there is no support to increase overall budgets. This means money would have to be taken away from another disease priority, and life science administrators have no desire to reduce funding for cancer or diabetes to allocate more to dementia.

Intense competition among healthcare priorities makes it especially difficult for public policy makers to invest heavily in a dementia crisis 20 years in the future. The corporate sector has no such constraint—and herein lies an opportunity.

The pharmaceutical industry invests approximately \$5 billion annually, or half of all R&D expenditures globally, with the remainder coming from governments, philanthropy and other private investments.

- Pharma excels at investing in targeted areas of research that offer high returns. The industry now has more than **300 agents** in development for dementia, from preclinical to phase III.
- **Additional incentives**—such as tax incentives, R&D credits and accelerated regulatory pathways—might be leveraged to encourage further industry investment the way pharma helped to expand research in rare

diseases, pediatric studies and other areas of unmet need.



Click for photo slide

Back now to what I and my colleagues on the World Dementia Council have achieved and our areas of focus.

During the first eight months of our tenure, we have delved deep into what's going wrong and how it can be fixed. At the end of our term next March, we will unveil what we see as our ground-breaking solutions.

There are five main areas for priority that I believe we must focus on, where real and tangible changes can be made.

First, research. How do we make sure effective treatments become available as soon as possible. Dementia is not just a life-changing condition, but a life-shattering one, so there really needs to be a smoother and faster process for drugs to move from early stage research through to prescription.

To this end, there has already been great progress. On Monday this week, for the first time ever, regulators from around the world met to discuss dementia drug development and making the pathway as innovative and integrated as possible.

It is essential that the research agenda includes regulators in this way, as well as industry and academic scientists to address gaps in our current development of innovative therapies. To stimulate more pharma investment, there is need to speed products to the status of provisional

approval in order to bring to the market more treatment options, and allow earlier returns on massive R&D investments.

This need for collaboration across academia and industry, public and private sectors was well illustrated at the second Global Legacy event in Canada in September, where we heard from a number of successful examples of where this has worked well, with how we can learn from each other.

The Canadian Consortium on Neurodegeneration in Ageing is one such example which has brought together public and private sectors to optimize research.

The problem we must tackle is that the basic science describing neurodegeneration is still under-developed, and until we have a clearer idea of specific targets in the brain, it is rather like finding a needle in a haystack to develop drugs. Initiatives around the world will help us to get there, such as the BRAIN initiative in the USA, which is funded handsomely and aims to map the entire workings of the brain.

The second priority is finance, namely the fuel needed to fire the engine of research and drug development. Poor investment in dementia has a simple explanation: the risks are too high, the rewards too low. Because drug

development is so lengthy, it takes too long for failures to become apparent, wasting huge amounts of money and time. Investors look to more fruitful areas of research. We need to reset that dial. A fund focused on accelerating preclinical products through Phase I may generate the most leverage to accelerate development of the therapeutic landscape.

At the first Global Legacy event in London in June, the focus was the impact of social finance and what should be done to maximize investment around the world.

Third is the priority of Open Science, structured around easy, one-step access to all of the global dementia data available. The potential of data is enormous when you think about how much is created in all areas of our work, from research and drug development, to best practice in care. At the moment, not enough science is shared globally. Not enough is shared across industry, across academic settings, and not enough partnering takes place between industry and academia. For example, when a clinical trial fails, that information needs to be available for other researchers to see, preventing mistakes from being repeated.

While the complex work on cure and financing it continues, there are reasons for optimism, particularly for those in middle age concerned about the chances of developing dementia. There is increasing evidence to show that you can significantly reduce risk by making modest changes to lifestyle, so my fourth priority is risk reduction.

The advice, “What is good for the heart is good for the brain,” may provide a solid basis for the guidelines to be followed. Lifestyle factors including increased physical activity, no smoking, moderate consumption of alcohol, efforts to learn new skills or knowledge, and a well-balanced diet may reduce the risk of cognitive decline. Diabetes, mid-life obesity and mid-life hypertension each show evidence that the risk of dementia is increased. Traumatic brain injury also increases the risk.

There are still some who question the evidence for some or all of these risk factors but, in my own view, the advice is common sense and can only lead to positive health. There is no downside. It is, of course, important to recognize that ardent adherence to risk guidelines cannot be guaranteed to prevent dementia for each individual. However, a balanced review of current literature suggests about a third of Alzheimer’s Disease cases may be

attributable to well-defined risk factors. This certainly provides short-term hope until more drugs become available.

The opposite end of the spectrum to prevention is care.

As the third Global Legacy event in Japan last week showed, the potential of technology in care is huge – and there are many exciting examples of robotic technology and advances in computer technology which allow carers to stay connected with patients remotely.

We can revolutionize **patient care** using technologies that **improve quality of life and reduce cost**. So, technology-enhanced care is my fifth priority. Robots are being developed to manage tasks from cooking and cleaning to bathing to meet growing needs for care and shrinking pools of caregivers.

- The Georgia Institute of Technology has developed “Cody” a robotic nurse designed to fetch objects and clean floors, but also gentle enough to bathe patients.
- In the U.K., the University of Reading built “Hector” who can remind patients to take medicine, keep track of their eyeglasses and assist in case of a fall.

In addition to providing care, robots could also be developed to provide reports of patient progress to caretakers and physicians.

1 click (for robot video)



Applications for **in-home and mobile devices** are evolving to assist both patients and caregivers:

- Wireless audiovisual networks and pocket personal computers can monitor a person's activity over time to track disease progression; monitoring systems can alert caregivers to safety issues such as falls and wandering.
- Smart phones can be used to contact and assist dementia sufferers with prompts to help them cope with everyday activities.

Coming back to the first priority, research, and what progress is being made. There *is* encouraging news. We do see an **uptick in research activity**.

According to data from BioPharm, the number of Alzheimer's trials has almost doubled this year, going from 350 trials in January to 634 in August. The number of patients participating rose from 340,000 to 478,000. The increase in patients participating in interventional studies is even more dramatic, roughly doubling.

This shows an increase in translational research. Discussions with Alzheimer's Societies suggest that patients are willing to participate in clinical trials, so

recruitment is not likely to be the problem it is in cancer. However, the specific targeting of patient populations needed for some areas of dementia research—particularly patients in a pre-onset stage—are likely to be challenging, driving up time and cost.

What I also find encouraging is the visibility of the research underway. The recent study by Carol **Brayne** at the Cambridge Institute of Public Health made it to the front page of the Daily Mail.

1 Click

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MANY ALZHEIMER'S CASES 'AVOIDABLE'

By PRESS ASSOCIATION

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2 Click (for article copy)

This research should prompt more investigations into the impact of blood flow to the brain on dementia, and the extent to which exercise could reduce risk, an important part of the prevention debate. Also identified is a small but detectable secular trend of a reduction in the incidence of dementia, when appropriately adjusting for age and other factors. This may be correlated with an associated improvement in the prevalence of some risk factors that

has been taking place in recent years. The Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability – affectionately known as the FINGER study – provides evidence from a randomized controlled trial that lifestyle intervention across a broad array of risk factors improves cognitive performance as well as executive function.

But it's not just scientific and therapeutic research that is needed, the younger generations must apply technology to revolutionize dementia research processes and patient care. Solutions will come from **Big Data, shared on Open-Source Internet Platforms** that connect researchers in global collaborations.

One is the “**Big Data Challenge**” launched by the Global CEO Initiative on Alzheimer's Disease in 2013. Partnering with IBM and Sage Bionetworks, the “Challenge” puts data, tools and evolving predictive models onto an open workspace and invites scientists worldwide to participate in “crowdsourcing” data analysis. The Alzheimer's Challenge focuses on identifying predictors of cognitive decline.

Another example is **Foldit**, an online game created by University of Washington, that is enlisting gamers to find

promising leads in Ebola research. Gamers tap into Foldit to solve puzzles, like finding the best ways to twist virtual protein molecules into desired shapes. Foldit gamers find solutions that computer algorithms miss. In the Ebola challenge, they've generated leads for the design of small cyclic peptides.

Advanced, real-time data platforms make it possible to revolutionize clinical research **methodologies and regulatory pathways** for dementia the way they are revolutionizing cancer studies. A dramatic example is the I-SPY 2 breast cancer screening trial. **I-SPY 2** is a collaborative Phase II research platform sponsored by FDA for use by multiple pharma companies and academic researchers. The trial uses adaptive designs to simultaneously evaluate drug candidates and quickly identify those with the best chance of extending disease-free survival. For dementia, such a platform could eliminate false leads faster and reduce duplicate effort.

Social media provides essential connections for dementia patients and their families—providing a forum for medical information, social support, advocacy and fundraising. A list of the “Top 10 Alzheimer’s Disease Social Media Resources” includes:

- the Alz.org resource center;
- Alzheimer's Association Youtube channel;
- "Had a Dad" Alzheimer's blog;
- Alzheimer's Study iPhone app.

Social media could be harnessed to further engage patient advocacy. For example access to regular and comprehensive analytical summaries of twitter feeds linked to dementia could dramatically increase the number of feeds and raise public awareness.

But it's not just awareness, advocacy can make a huge difference in funding, just as it did for AIDS research. Who ever thought that a bucket of ice could be so valuable. The ALS ice-bucket challenge has raise more than \$115 million dollars for ALS research. It's also brought together people of all ages together for a common cause.

Click (for video montage)



In the UK, there is a way of bringing people of all ages together to tackle dementia. It's called Dementia Friends.



I took the Dementia Friends course earlier this year. The intent is to restore the connections between dementia patients and their friends, their family and their everyday lives. It's a way of raising awareness and also a call to action – giving guidance on how to help make life easier.

There are now over 600,000 dementia friends in England and over 70 dementia friendly communities. As we have

more Dementia Friends, the more of these dementia-friendly communities we can create.

The initiative was born in Japan, where there are over 5 million people who have taken the training. Canada too has now adopted the scheme, and I would love to see more countries around the world doing the same.

And that brings me back to where I started. It's going to take all of united in one community to commit to defeating it.

Our goal must be to **deliver a generation of progress in a decade**. I know you will join me.

Thank you.