

# DEMENTIA

Meeting of the Parliamentary and Scientific Committee on Tuesday 9th December

# THE CHALLENGE OF DEMENTIA



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**Dementia affects about 800,000 people in the UK. When you include people around a person with dementia, that number can be multiplied by two, three or four. Almost everyone knows of someone with dementia.**

Awareness of dementia is at its highest. The Prime Minister’s challenge was launched in March 2012 which highlighted the need for improved diagnosis, more research and reducing stigma.

Just over half the estimated number of people with dementia receive a formal diagnosis and there is significant variation across the country (figure 1). NHS England has an ambition that two thirds of the estimated number of people with dementia receive a diagnosis and post diagnostic support.

### Research funding has also increased

For people over the age of 50, dementia is the most feared illness, more than cancer or heart attacks. Figure 3 outlines some of the effects that dementia can have on people. “Dementia friends” (dementia friends.org.uk) is a nationwide initiative which is a social movement to raise awareness of dementia and reduce the stigma associated with it. The ambition is to have one million “dementia friends” by March 2015. This emphasises that there is more to a person than dementia, that dementia is not an inevitable part of ageing, and that people can live well after receiving a

diagnosis of dementia (Sir Terry Prachett continued to write his very successful novels and was knighted while he had dementia). Look at the

Alzheimer Society website (alzheimers.org.uk), or the dementia friends website (dementia friends.org.uk).

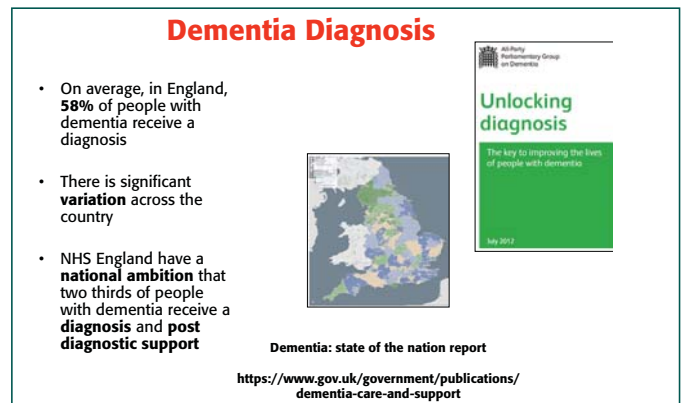


Figure 1



Figure 2



Figure 3

### Three things are important in dementia: how do we diagnose it, how do we treat it and can we prevent it?

First, the diagnosis. Dementia is a way of simply describing a group of symptoms (of which people sometimes complain) and signs (which clinicians notice). The commonest cause of dementia is Alzheimer's disease (probably in just over half of people) followed by vascular dementia (where the blood supply to the brain is severely restricted which may also cause strokes). Other causes are less common such as Lewy body dementia (where there are some symptoms related to Parkinson's disease and a person may have persecutory ideas and episodes of confusion) and dementia of the frontal lobe type (where the front part of the brain is

### ... dementia is the most feared illness ...

selectively affected and the main symptoms are related to changes in personality and behaviour).

The initial symptoms of dementia vary depending on its cause. For example, symptoms of Alzheimer's disease usually start very gradually with loss of memory. It can sometimes be a challenge to decide whether these are symptoms of memory loss, which can occur with normal ageing or if it is the early signs of Alzheimer's disease.

Generally speaking, minor lapses of memory which occur from time-to-time and do not get worse very quickly are part of the normal process of ageing. Something which happens

much more regularly (most days), tends to get worse over a period of months, and is noticed by others, is less likely to be part of normal ageing. If a person is worried, they should seek advice from their own doctor in the first instance. People with vascular dementia tend to develop the symptoms much more suddenly and these may be more related

to inability to perform tasks of everyday living rather than just memory problems. People with Lewy body disease also tend to develop symptoms quickly and there can be episodes of confusion and symptoms of Parkinson's disease

When a person presents to their GP with symptoms, there are several things which need to

be investigated. Sometimes, depression in older people can give rise to symptoms similar to dementia (low mood, lack of enjoyment in things, loss of weight, early morning wakening, crying and not looking forward to the future) and these symptoms need treating energetically. Also, there could

be a physical cause of the symptoms such as a low level of vitamin B12 or an underactive thyroid gland, diagnosed with a simple blood test and easily treated.

Second, what can be done to treat dementia? If there is

depression or physical illness present, this can usually be treated in a simple and straightforward way. There is no specific drug treatment for vascular dementia although the following will help, both in terms of reducing further memory impairment, but also in reducing the risk of heart attacks and strokes: controlling high blood

### ... symptoms of dementia vary ...

pressure and high cholesterol; treating any sugar diabetes; encouraging people to lose weight if necessary; to take more exercise and; to stop smoking. In terms of the

treatment for Alzheimer's disease, there are four drugs which are available – three are from the same class of agent (cholinesterase inhibitors which are drugs that stop the breakdown of acetylcholine in the brain therefore raising its level and improving symptoms).

The three drugs currently available are donepezil, galantamine and rivastigmine. The drugs are modestly effective when you examine a group of people with Alzheimer's disease

### ... evidence base for them is not quite as strong ...

but, often, the response of individuals can be very pronounced. The improvement in symptoms is seen over weeks and months rather than hours or days. In some people, the symptoms improve, in others the drugs seem to slow

down the progression of the disease but in some they do not seem to have any effect. The fourth drug (memantine) acts on the glutamatergic receptors.

There are also non-drug approaches to symptoms and these tend to be very popular but the evidence base for them is not quite as strong as for medications. However, it is important to support people with dementia and their carers following diagnosis of dementia. There is good evidence that giving people support can improve the stress and strains of being a carer and also can improve the symptoms, and can prevent a crisis happening.

### ... what can be done to treat dementia? ...

Treatments like bright-light therapy, aromatherapy, cognitive stimulation therapy and reminiscence therapy all fall into the category of 'talking treatments' which can be helpful in alleviating symptoms.

Third, in terms of prevention of dementia there is much that can be done. There is evidence that reducing vascular risk factors like the ones mentioned above, can reduce the rate of strokes and heart attacks and reducing these medical conditions will reduce the rate of dementia. There is also evidence to suggest that it will reduce the rate of Alzheimer's disease as well as vascular dementia. In addition to the measures mentioned above, there is some evidence that, in general cardiovascular terms, drinking a moderate amount of alcohol is of benefit to you, but drinking to excess will cause a form of dementia.

# DEMENTIA RESEARCH: Progress and Challenges



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### WHY IS DEMENTIA RESEARCH NEEDED; WHAT MIGHT IT ACHIEVE

The impact of dementia upon individuals – those who are living with it as well as their families and dependents – can be devastating. The wider societal and economic impacts are also very significant (nearly £24 billion a year in the UK<sup>1</sup>) and are likely to increase. The impacts of dementia will put even greater strains upon health and social care systems. Whilst remedial planning and action are needed here, and this will be neither simple nor cheap, research into the causes of dementia offers a solution to reducing these impacts.

*... depends on an accurate and timely diagnosis ...*

Dementia presents a great unmet medical need. Current treatments are limited both by the degree and duration of their effectiveness, helping some with dementia with some of their symptoms for some of the time. Access to current treatments (or to any improved treatment of the future) depends on an accurate and timely diagnosis. Whilst progress is being made, the limitations of current diagnostic procedures present a clear need for research-led improvement.

Taking a public health perspective, the results of epidemiological studies and

other types of research are offering the prospect of risk reduction<sup>2</sup>. Much evidence points towards risk reduction which approaches that for other chronic illnesses. While these approaches will not work for everyone, even a modest proportional reduction in risk at a population level could have a positive impact on a large number of individuals. This will benefit from a stronger evidence base.

### WHAT CHALLENGES DOES DEMENTIA RESEARCH PRESENT?

From a scientific point of view, one of the greatest challenges is that dementia is a disorder of the brain, our most complex

organ and one which is inherently difficult to study and to treat. Dementia is not a single disease, or even a disease at all – it is a syndrome, a collection of symptoms which result from underlying and varied causes. The most common of these is Alzheimer's disease. Most dementias are associated strongly with increased age and so are complicated by other processes or conditions which can also accompany the ageing process. In Alzheimer's disease and in other dementias, there is a long and silent phase during which changes in the brain occur before the onset of any

symptoms. Researching the early events in the brain which lead to dementia is difficult since it is not clear who is undergoing these changes, and therefore whom to ask to volunteer.

Despite the unmet need, dementia research is seen as small, underfunded and unattractive. Previous work commissioned by Alzheimer's Research UK suggested that for every one researcher working in dementia, six work in cancer research<sup>3</sup>. This is true of academic research funded by government agencies and charities. Recent history within Pharma shows a very high failure rate of candidate treatments, and, given the complexity of development, the risk/reward ratio is often deemed too high, despite the huge potential rewards should a treatment be even moderately efficacious. Dementia research has been viewed as difficult and unattractive across all sectors.

### WHAT HAVE WE LEARNED SO FAR ABOUT THE DISEASES WHICH CAUSE DEMENTIA?

Like many other chronic illnesses, a complex interplay of genetic and environmental risk factors are behind the development of dementia. Age remains the biggest single risk factor in most cases.

Alzheimer's and Parkinson's disease (which can often lead to dementia) as well as rarer

dementias such as Dementia with Lewy Bodies, Frontotemporal dementias and prion disease (CJD) are characterised by the damage to, and death of, nerve cells in the brain caused by an abnormal build up of specific proteins. This process is called neurodegeneration. The type of protein and the parts of the brain affected define the disease type and the symptoms.

### *... Dementia is not a single disease ...*

The second most common dementia is vascular dementia, which results from damage to, and death of, brain cells following impaired blood supply. There is some overlap here with stroke but rather than a dramatic and sudden event, the damage seen in vascular dementia can be low-level, but cumulative. 'Mixed dementia' of more than one cause or type is not uncommon (eg Alzheimer's and vascular). This presents an additional challenge for any treatments. In dementia, as with a range of other chronic illnesses, there is increasing recognition of a role for the inflammation which may exacerbate disease process.

### *... inflammation which may exacerbate disease ...*

These dementias are progressive and irreversible. It would be very attractive to think of a single 'cure-all' treatment which could protect nerve cells from dying in any dementia. However, the common underlying mechanisms are not well understood and most attention has been focused on the different upstream causes, particularly in Alzheimer's disease.

## **WHAT IS NEEDED TO ACHIEVE THE GOALS OF BIOMEDICAL DEMENTIA RESEARCH?**

If we wait until we fully understand all the science behind dementia before trying to develop new treatments, we will be waiting too long. We should keep looking for new treatments based upon what we know already – and most of this knowledge is of Alzheimer's disease. However, there is an

urgent need to investigate new disease mechanisms and consequentially, to accelerate the identification of new drug targets. In parallel, we need to develop new ways of detecting and measuring different dementia pathologies in people who may not be showing overt symptoms or who are in the earliest stages. Whilst these may eventually have some clinical diagnostic or prognostic use, more immediate uses are in research – such as the identification and stratification of participants in clinical trials as well as tracking the efficacy of new treatments. Brain imaging is already making significant progress to these ends. Efforts

are taking place to find other 'biomarkers', for example in cerebrospinal fluid or even in blood. Neuropsychological tests may also offer more sensitivity and specificity in measuring subtle, early cognitive changes caused by dementia.

Beyond the purely scientific, there are other important considerations if we are to see

new treatments for dementia:

- The environment, support and infrastructures for challenging types of clinical trials with a vulnerable patient group
- Incentivising investment from Pharma/Biotech.

This could be through private/public partnerships in which early findings from academic research have a clear and facilitated path towards commercial drug discovery and development. Regulatory incentives may also be needed.

- Funding streams to attract and retain researchers in dementia research and to promote the translation and implementation of outputs.

Alzheimer's Research UK is committed to addressing many of these points<sup>4</sup> but the scale of

### *... Brain imaging is already making significant progress ...*

challenge demands a variety of responses and participants. In recent years there has been unprecedented interest and activity surrounding dementia and dementia research. In the UK, the Prime Minister's Challenge on dementia has brought additional research funding. The UK used its recent G8 presidency to raise the international profile of dementia research, culminating in a pledge to find a cure or 'disease-modifying' treatment by 2020. The G7 countries subsequently spearheaded three Global Action Against Dementia events focused on harnessing the momentum created by the UK presidency and galvanising activity across the globe. To sustain this legacy a World Dementia Envoy and World

Dementia Council have been appointed, with a remit to support co-operative work between G7 countries, and beyond, to incentivise investment in research.

Despite the large and many challenges, we must capitalise on these opportunities. The UK is well placed to play its part. We owe it to the 44m people worldwide who currently have dementia and to future generations.

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- 2 *World Alzheimer Report 2014: Dementia and Risk Reduction*; Alzheimer's Disease International <http://www.alz.co.uk/research/world-report-2014>
- 3 *Defeating Dementia* (2012); Alzheimer's Research UK <http://www.alzheimersresearchuk.org/defeating-dementia>
- 4 *The Power to Defeat Dementia 2015-2020*; Alzheimer's Research UK Manifesto [http://www.alzheimersresearchuk.org/siteFiles/resources/documents/reports/AlzheimersManifesto\\_Webversion.pdf](http://www.alzheimersresearchuk.org/siteFiles/resources/documents/reports/AlzheimersManifesto_Webversion.pdf)

# DEMENTIA: ECONOMIC CONSIDERATIONS



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**Dementia is costly. The costs (to the public purse as well as to individuals) will get considerably greater as the population ages. This has focused the minds of many governments on ways to contain those costs, whilst ensuring that people with dementia and their carers can live well. What needs to be done to achieve that important goal?**

## COSTS

The annual cost of dementia in the UK today exceeds £26 billion (Prince et al 2014). Costs to the NHS are substantial, equivalent to almost 4% of total health spend in the country, but costs to the social care sector are 2.5 times higher. More than half the social care cost falls directly to the people who use services (as self-funders or through user charges). But the largest cost is the time spent providing care and support by unpaid family members and other carers.

Some of these costs are welcome, others not. The ‘good costs’ represent the appropriate, evidence-based treatment and care responses to assessed

needs. The ‘bad costs’ result from late or no diagnosis, unavailability of effective care, crisis admissions to hospital and unnecessarily long inpatient stays. It is hard to calculate the relative sizes of the ‘good’ and ‘bad’ costs, but as a society we surely want to shift the balance from the latter to the former, by developing, and making more widely available, good quality (evidence-based) treatment and care arrangements.

The need to shift the cost balance is obvious if we look at future projections of dementia prevalence. There are 816,000

people with dementia in the UK today, and that number will double in 25 years. Even though the age-specific prevalence rate might be slowing (Matthews et al 2013), the total number with dementia will still grow rapidly as the population ages. Consequently, unless we can do something to change those trajectories, there will need to be even greater reliance on unpaid carers and big increases in health and social care service costs.

## RESPONDING TO THE CHALLENGE

The figures summarised above are just aggregates. They are not cost-effectiveness findings. They do not tell key decision-makers what they might do to improve

the situation for individuals affected by dementia, or how to make better use of resources.

There are several options for reducing future costs and improving lives. One is risk-reduction: reducing the number of people who develop dementia, or delaying the age at which the condition interferes significantly with their lives. Known risk factors for the development of Alzheimer’s disease and other dementias include diabetes, mid-life hypertension, mid-life obesity, physical inactivity, depression, smoking and low educational

attainment. Norton et al (2014) estimate that ‘around a third of Alzheimer’s Disease cases worldwide might be attributable to potentially modifiable risk factors’.

Another strategy would involve more timely identification of dementia and better screening (ie faster responses to early signs of dementia, and better screening tools to improve diagnostic accuracy). This would undoubtedly help individuals to plan their lives and should also enable them to get better health and social care support, although access remains variable across the country. Timely diagnosis might therefore also head off some crisis-related costs.

Post-diagnostic support is where most of the costs of dementia arise: this support encompasses all community and other health and social care services that people with the condition might use, plus unpaid support from carers. It also includes costs of care home residence and hospital inpatient admissions. Those latter costs can be huge, but the benefits for quality of life and health can also be substantial.

We now have a small body of robust evidence on what works in post-diagnostic support. Research has focused on areas such as carer support, staff skills, symptomatic medications, psychosocial treatments, better home-based care (including

growing interest in, but not much evidence on assistive and information technologies) and care co-ordination. We also now have a body of *economic* evidence, helping us to recognise what resource consequences might flow from those interventions (Knapp et al 2013).

## SUPPORTING FAMILY CARERS

An example of new evidence that can provide guidance to

*... more timely identification of dementia ...*

commissioners and other decision-makers comes from a study of START: an intervention to help family carers of people with dementia to develop better coping strategies. It was delivered by psychology graduates, with each carer having eight one-to-one sessions. Carers were given information on where to get emotional support, and taught (personalised) techniques to improve their understanding and manage the behaviours of the person they cared for, change unhelpful thoughts, promote acceptance, improve communication, plan for the future, relax and engage in meaningful enjoyable activities.

*... head off some crisis-related costs ...*

START was evaluated over 24 months in a randomised controlled trial in North London and Essex. Results were very positive. Carers who received START had significantly better health-related quality of life and better mental health by the 24-month follow-up point than carers who got usual support. There were no effects (negative

or positive) on people with dementia (illness severity, neuropsychiatric symptoms or quality of life). And START was clearly cost-effective. Although service costs went up over time for people in both the intervention and control groups - which is not surprising given how dementia usually progresses - overall, the START intervention was no more costly than standard support arrangements.

## NEW SCENARIOS

My colleagues and I recently examined the economic consequences of different scenarios for future dementia care (Knapp et al 2014). Some scenarios looked at the wider availability and use of evidence-based interventions, while others looked at the consequences of introducing a disease-modifying treatment (as yet undiscovered) with the potential either to slow disease progression or to delay its onset.

When we looked at the wider availability of interventions such as anticholinesterase inhibitors, cognitive stimulation therapy, case management and carer support, we found that the

overall impact nationally was actually rather modest in cost terms, although with important improvements in health and quality of life. In other words, more widely implementing what we know today to be effective and cost-effective would definitely improve the situation for people with dementia and/or their carers, but it would not

bring down the total cost 'bill' of dementia by any noticeable amount.

On the other hand, a disease-modifying treatment - or, indeed, a risk-reduction strategy - that delayed onset by a year or longer would bring down costs substantially. Slowing the progression of the disease would also potentially reduce costs, because it would delay the need for people to go into care homes or hospital. There would also be gains in health and quality of life for the individuals at risk of developing dementia and their families.

However, disease-modifying treatments do not yet exist, and it is difficult to conjecture when they might become available. It is also difficult to know what they might cost per patient. A high price for a new disease-modifying medication, for example, would considerably reduce (indeed perhaps

completely wipe out) the savings on care costs that would be suggested by slowed progression or delayed onset.

## MODEM

With colleagues at LSE and other universities, I have recently started a study which will be projecting numbers of people with dementia from now to 2040, the costs of supporting them and the quality of life outcomes under present care, support and treatment arrangements. We will then explore what would happen in cost and outcome terms if better interventions were more widely available. We will run through the scenario exercise described, but now projecting

over a 25-year period, exploring a wider range of potential interventions (including risk-reduction), and carrying out more exacting analyses.

This is the MODEM study. It is funded by the Economic and Social Research Council and the National Institute for Health Research. It will start to generate findings in the next couple of years, and provide a platform of evidence to inform decisions about how the country can develop affordable, effective and cost-effective systems of care and support.

## POLICY RESPONSES

In England we have been fortunate over recent years to have had two well-structured policy frameworks: the National Dementia Strategy (Department of Health 2009) and the Prime Minister's Challenge on Dementia (Department of Health 2012). A new dementia

*... understand the aetiology of the various dementias ...*

policy ('Vision') is currently being discussed for England, offering suggestions for how society can best respond to dementia over the coming years.

In parallel, on the international stage, the G8 countries - along with the OECD and WHO - have committed to collaborative action to address the dementia challenge. This includes setting up the World Dementia Council. The Council (of which I am a member) is looking for ways to improve finance for investments in new treatments, better care, research collaboration (across governments, academics and industry), harmonised regulatory pathways to accelerate drug development, sharing data,

identification and dissemination of best practice, and awareness-raising with respect to the economic and social challenges of dementia.

## A THREE-PRONGED FUTURE

I have mostly concentrated on economic issues, although set in their wider context. We know that dementia is a major, world-

*... START intervention was no more costly ...*

wide challenge for health and care systems, and for societies more generally. Unless someone suddenly discovers an affordable cure, those challenges will get considerably bigger over the next 40 years. The costs of dementia will also increase considerably. That will

necessarily include the (often hidden) burden falling on unpaid family and other carers.

Efforts to understand the aetiology of the various dementias need as much support as we can muster, as do efforts to find biomarkers and treatments. We urgently need to understand what risk-reduction strategies might be effective,

and how best to implement them. We also need to know what care and support arrangements work best. Then we need to assess whether they represent cost-effective uses of society's always scarce resources.

The policy imperatives are clear, if slightly daunting. If the overarching objectives are to achieve better health and quality of life for people with dementia – indeed for everyone – and to make the best use of resources, then we need a three-pronged strategy to reduce risk, improve care and find a cure.

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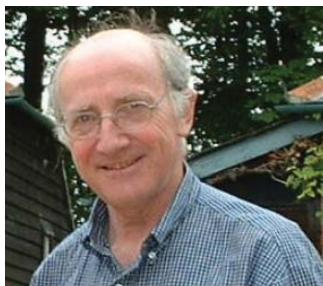
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# HOUSE OF LORDS SCIENCE AND TECHNOLOGY SELECT COMMITTEE



The members of the Committee (appointed 12 June 2014) are Lord Dixon-Smith, Baroness Hilton of Eggardon, Lord Hennessy of Nympsfield, Lord O'Neill of Clackmannan, Baroness Manningham-Buller, Lord Patel, Lord Peston, Lord Rees of Ludlow, Viscount Ridley, the Earl of Selborne (Chairman), Baroness Sharp of Guildford, Lord Wade of Chilton, Lord Willis of Knaresborough and Lord Winston.

## Resilience of Electricity Infrastructure

In July 2014, the Committee launched an inquiry into the resilience of electricity infrastructure. The inquiry is focusing on the resilience of the UK's electricity infrastructure to peaks in demand and sudden shocks. It is interested both in the short term (to 2020) and in the medium term (to 2030) as electricity generation is decarbonised. Oral evidence was taken until late January 2015 and the Committee will report by the end of the Session.

## 2025: Priorities for Scientific Research

In July 2014, the Committee conducted a short inquiry looking at the key challenges that the Government's forthcoming *Science and Innovation Strategy* should tackle and the UK's

main priorities for scientific research. No report was produced but evidence was taken in public and transcripts were published and brought to the Government's attention.

## Behaviour Change

In May and June 2014, the Committee took oral evidence from a small number of witnesses to follow up on its 2011 report into behaviour change and assess what progress has been made in this area. This focused on the two behaviour change case studies that the Committee had investigated in its original inquiry: modal shift in transport and obesity. The Committee wrote to the Minister for Government Policy, Rt Hon Oliver Letwin MP, in July, making a number of observations and posing a series of questions, and received a reply.