

The Future Economic, Health and Social Care Costs of Dementia

ILC-UK and the Actuarial Profession
Joint Debates held in London and Edinburgh

June 2011
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The International Longevity Centre - UK (ILC-UK) is an independent, non-partisan think-tank dedicated to addressing issues of longevity, ageing and population change. It develops ideas, undertakes research and creates a forum for debate.

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CONTENTS

Executive summary	4
Infographic summary	6
Speakers	7
Setting the scene	8

The costs of dementia

The big picture costs	12
Medical costs	14
Investment in dementia	16
Hidden carer costs	18
The humanitarian costs	20

Priority themes

The context	22
Early Diagnosis	24
Care Models	26
Holistic approaches	28
Rethinking support	30
Prevention	31

Where next

Summary of recommendations	33
Voting results	35
Videos and links	37
Reference links	38

EXECUTIVE SUMMARY

This report is the product of two joint debates hosted by ILC-UK in partnership with the Actuarial Profession in Edinburgh and London, held in February and March 2011. The debates and report were supported by Pfizer in the UK.

The current cost of dementia represents 1% of Global GDP and this cost is set to rise substantially: in 2001 it was estimated there were twenty four million people with dementia worldwide, and by 2021 that number will have doubled. Such escalations in numbers and associated costs are set to produce an unsustainable situation. The tipping point has been reached, and as expressed by Martin Prince, Professor of Epidemiological Psychiatry at Kings College London, the long-term care needs for older people present the single largest global threat in the 21st century; high income countries will soon see their sovereign debt rating affected unless they take action.

In the wider health and social care context, the outlook is similarly concerning. The proposed reform in the way the NHS, GPs and local authorities are to commission services, coupled with the perennial question of how to fund social care, currently being examined by the Dilnot Commission, creates a climate of uncertainty.

Do we think that policy-makers and politicians are tuned into the issue? Certainly, dementia and long-term care have risen from the policy lacunae, but the concern is that the big issues are still not being tackled seriously. In a poll of attendees at the London debate, 93% of delegates either disagreed or strongly disagreed that the Government is prepared in terms of long-term strategies to respond to the increase in the number of people with dementia.

With the debate convened to interrogate these issues, this report begins with an examination of the costs of dementia, both direct and indirect.

Beginning with the medical costs, we see that people with dementia stay in hospital longer than necessary. The Kings Fund suggests that £300 million would be released from hospital budgets if we could keep individuals with dementia from going into hospital when they do not need to be there.

With regard to informal care costs, the bedrock of dementia care comes from unpaid carers which account for 55% of total costs. We also see high humanitarian costs arising from this care burden. In tighter financial times, are people going to give up work to care? Can they afford to do so?

Yet despite these costs, dementia funding is not comparable to the burden of the disease. Of the top four diseases (dementia, cancer, stroke, heart disease), dementia contributes 52% of the costs, but receives only 6% of funding.

From this scene-setting, the report identifies policy priorities, which include support for early diagnosis, increased awareness-raising on dementia amongst the health and social care profession, more effective and tailored support for carers, and the need for a prevention agenda for all ages. Overall we require a holistic approach; older people with

dementia can have a quality of life and should be supported in this as individuals and family and community members, particularly through the provision of dementia advisors and by enabling them to stay at home if supported.

There is certainly a need to look at how to save money in dementia care and deliver better outcomes for people, especially in light of the difficult fiscal climate for public services, yet there is also an argument for spending now in order to save later.

Notes on this Report:

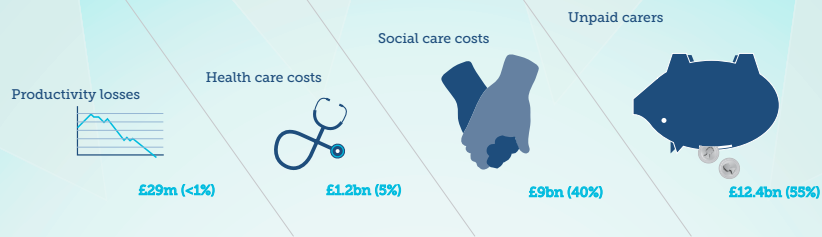
Capturing the most important conversations and comments, this report is structured by theme rather than by speaker, so that readers may access those sections most relevant to their interests. The debates were enhanced through the use of social media, so in addition to speaker arguments and questions from the floor, the document incorporates quotes, audio excerpts and video clips. An introductory infographic diagram, meanwhile, distills the headline statistics to which speakers referred.

For the purposes of editorial clarity, quotes when labelled as such are direct, whereas 'key points' are distilled summaries of ideas conveyed by the speakers; these are not direct quotations. Comments came both from questions in the room, and online interactive tools including twitter and the liveblog.

Please also note, a range of estimates have been made of the numbers of people with dementia living in the UK and the financial costs associated. King's College London and the London School of Economics in a report to the Alzheimer's Society using UK population study data estimates that there are 750,000 people living with dementia in the UK and that the financial cost is £20 billion a year. This contrasts with the Oxford University study which is reported in this report and used European population study data and estimates that there are 820,000 people living with dementia in the UK at a cost of £23 billion.

The economic and social costs of dementia.

Dementia cost the UK economy £23bn in 2008: ¹



The average cost of dementia per person = **£27,647** per annum

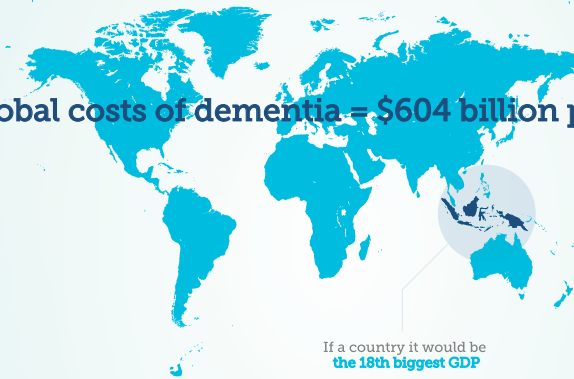


The average UK salary per person = **£24,700** per annum ²

In a survey of nursing staff and managers **97%** of respondents say they **always or sometimes** care for someone with dementia ³

"dementia is the **only** disease classified as a **social care issue** rather than as a **health issue**" ⁴

Global costs of dementia = **\$604 billion per year** ⁵



Dementia directly affects over **820,000** people in the UK ⁶



only 40% are being diagnosed



if this doesn't improve, there will be **1/2 million undiagnosed in 10 years** ⁷

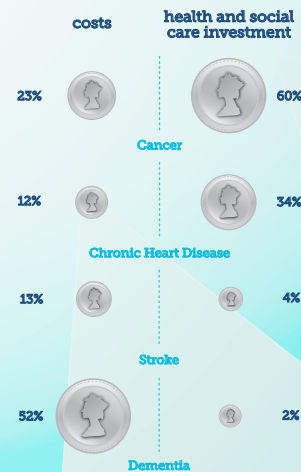
At the ILC-UK's 2011 London debate on dementia costs,

93.5% of the audience **did not think the Government is prepared** with long-term strategies to respond to the increase in the number of people with dementia ⁸

50,000 = the number of people **living with dementia** who may go **unnecessarily** into long-term care

£121 million = saving society could make on **care home places** every month if they were supported to remain at home ⁹

Cost vs. research investment in four major diseases ¹⁰



Footnotes:

1, 2, 6, 10: Luengo-Fernandez R, Leal J, and Gray A (2010) 'Dementia 2010: the economic burden of dementia and associated research funding compared with other major diseases', Alzheimer's Research Trust.
3: Respondents to Dementia Hospital Research (DEMROS) conducted for Alzheimer's Society (2009) 'Counting the Cost'
4: Jeremy Hughes, Chief Executive, Alzheimer's Society at ILC-UK London debate, March 2011

5: Wilmo A and Prince M (2010) 'World Alzheimer Report 2010', Alzheimer's Disease International
7: Alzheimer's Society, Alzheimer's Scotland and Tesco (2011) 'Dementia prevalence and diagnosis rates map'
8: Live poll of ninety audience members conducted by ILC-UK
9: Alzheimer's Society (2011) 'Support. Stay. Save. Care and support for people with dementia in their own homes - economic model'



SPEAKERS

EDINBURGH:

Chaired by Stewart Ritchie

Past President of the Faculty of Actuaries

Professor Martin Prince

Professor of Epidemiological Psychiatry, Institute of Psychiatry, King's College London
Co-Director, King's Health Partners and London School of Hygiene & Tropical Medicine
Centre for Global Mental Health

Professor June Andrews

Director of Dementia Services Development Centre, Department of Applied Social
Science, University of Stirling, Scotland

Henry Simmons

Chief Executive, Alzheimers Scotland

LONDON:

Chaired by Baroness Sally Greengross OBE

Chief Executive of ILC-UK

Co-chaired by Ian Sissons

Head of Munich Health, UK and Ireland

Dr Ramon Luengo-Fernandez

Senior Researcher, Health Economics Research Centre, Department of Public Health,
University of Oxford

Professor Alistair Burns

National Clinical Director for Dementia, Department of Health, Professor of Old Age
Psychiatry, University of Manchester

Jeremy Hughes

Chief Executive, Alzheimer's Society

Emily Holzhausen

Director of Policy and Public Affairs, Carers UK

SETTING THE SCENE

Dementia is described as the most significant health and social care crisis of the twenty-first century. ‘We have reached a tipping point’, is how Jeremy Hughes, Chief Executive of Alzheimer’s Society, describes the situation.

The statistics:

- Dementia directly affects over 820,000 people in the UK.¹
- In 2001 there were 24 million people with dementia worldwide, with that number set to double in 20 years.²
- New estimates suggest that by 2050, 115.4 million people will be living with dementia.³
- Dementia is the leading chronic disease contributor to disability and to dependence for care.⁴

Questions to the debate - from Baroness Sally Greengross:

What should be the core set of policy principles which guide the formulation of dementia policy in the coming years?

What policy interventions have been shown to be cost effective and how do we make a case to policy-makers, for example, with regard to early diagnosis, effective support and services and investment in research?

If it is possible to delay the onset of dementia for example, will that save money in the long-term?

How do we measure the economic benefit of policy interventions, not only in terms of net savings, but in terms of the positive outcomes for the patients’ families and caregivers?

What will be the impact of new technologies for people with dementia and their families?

Is preventative healthcare cost-effective for older people, particularly with regard to dementia?

¹ Alzheimer’s Research Trust Dementia 2010 figures

² From The Lancet, 2005, as quoted by Professor Martin Prince

³ Statistic given by Professor Martin Prince

⁴ Statistic given by Professor Martin Prince

How will the frontier of our knowledge and understanding of dementia change in coming decades?

Comments:

“There’s clearly a lot of education that all of us can take on board and we need to do that really over the next few years, because it’s so predictable that it’s going to be such a big problem in the relatively near future.”

Stewart Ritchie, Past President, the Faculty of Actuaries

“We’re prepared to put up with a level of support for dementia we wouldn’t accept for any other disease - we’ve allowed ourselves to be lulled in to this sense that dementia isn’t so important. We’ve become complacent and we have a lot of catching up to do.”

Jeremy Hughes, Chief Executive, Alzheimer’s Society

THE COSTS OF DEMENTIA

THE BIG PICTURE COSTS

We can see the costs of dementia as those we know and can measure, against those that are hidden. It is the latter, often related to long term care costs which may present the biggest challenge.

The Statistics:

- Dementia cost the UK economy £23bn in 2008 - greater than the costs of cancer and heart disease combined. (cancer cost £12bn, heart disease £8bn and stroke £5bn) ⁵
- The current cost of dementia represents 1% of Global GDP.⁶
- With an ageing population costs are set to soar even further - by 20% over the next 15 years.⁷



Key Points:

- Long-term care needs for older people present the single largest global threat in the 21st century. High income countries will soon see their sovereign debt rating affected unless they take action. (Professor Prince)
- When only focussing on health and social care costs, dementia is much more costly than cancer. Though its healthcare costs are lower, the high care burden influences its overall cost. (Dr Luengo-Fernandez)
- Internationally we see varying cost-distributions between high-income and low-income countries. In the former, medical healthcare is a small cost, while the direct cost of social

⁵ The economic cost and research funding of dementia compared with other diseases, Ramón Luengo-Fernández, University of Oxford HERC

⁶ Alzheimer's Research Trust Dementia 2010 figures, as quoted by Sally Greengross

⁷ Quoted from Jeremy Hughes, Alzheimer's Society

care predominates, along with the cost of carers. For the latter, direct costs have more or less evaporated as these countries do not traditionally provide care from the state, and informal costs comprise 2/3 of the burden. (Professor Prince)

- Poorer countries in the EU are those where dementia is relatively less expensive. In countries such as Greece, Portugal, Spain and Italy, the families shoulder more of the responsibility, bringing lower institutionalisation costs. (Professor Prince)

MEDICAL COSTS

Though medical costs are proportionally lower than the long-term care burden, too many individuals with dementia are admitted to hospital unnecessarily, adding additional costs to the health system.

The Statistics:

- People with dementia stay in hospital on average for one to four weeks longer than other people admitted with the same health problems.
- The Kings Fund suggests that £300 million will be released from hospital budgets if we can keep dementia patients from going into hospital when they don't need to be there.⁸
- In the UK 50,000 people with dementia per year are going in to institutions too early, to a cost of £70m each month.⁹
- 47% of people said when the person they are caring for goes into hospital, this creates more health problems for the individual with dementia.¹⁰
- Every year 1,800 people with dementia die prematurely, and 1600 people experience a stroke, as a result of antipsychotic drug prescriptions.¹¹

Key Points:

- Dementia patients may be given antipsychotic drugs in hospital to make life easier for untrained hospital staff, and they are remaining on the drugs when they are released from hospital. (Jeremy Hughes)
- The risks and side effects of these drugs are under-reported due to the lower profile of dementia - "If this were cardiology, it would be on the front pages." (Professor Burns)
- Up to £80 million in the UK could be released if we reduced the use of anti-psychotic drugs. (Dr Luengo-Fernandez)
- It could be that those with dementia receive inconsistent care in hospital compared to general admission patients. If admitted with a fractured hip they may receive less pain relief than an individual without dementia. (Professor Andrews)

⁸ statistic given by Jeremy Hughes, Alzheimer's Society

⁹ statistic given by Jeremy Hughes, Alzheimer's Society

¹⁰ statistic given by Jeremy Hughes, from Alzheimer's Society report

¹¹ statistic given by Professor Alistair Burns

- A contributing factor could be that few hospitals have mandatory training specifically on treating people with dementia, according to The Royal College of Psychiatrists' 2010 report. (Professor Burns)
- Hospitals can be considered to be dangerous places for those with dementia - once you fall into needing the care provided by a hospital it is hard to ever get back to full health. If hospitals can optimise their system to care for people with dementia, they will have optimised it for everyone. (Professor Andrews)
- Many dementia patients are admitted with physical health issues which would not on their own necessitate hospitalisation, but which become higher priority because of their care requirements. Therefore there are a lot of dementia sufferers in hospital who perhaps do not need to be there, with corresponding impact on both NHS costs and the patients' quality of life. (Professor Burns)

Comments:

"We don't have a health and social care system, we have a crisis intervention system, which doesn't act well for the benefit of people. It also costs more than it would otherwise cost"

Jeremy Hughes, Chief Executive, Alzheimer's Society

INVESTMENT IN DEMENTIA

Considering its cost impact, dementia research is severely underfunded compared to other major diseases.

The Statistics:

- Research spending for every £10 spent on health and social care was £1.29 for cancer, 73p for CHD, 5p for Dementia and 9p for stroke.¹²
- Overall, of the top four diseases (dementia, cancer, stroke, heart disease), dementia contributes 52% of the costs, but receives only 6% of the funding.¹³

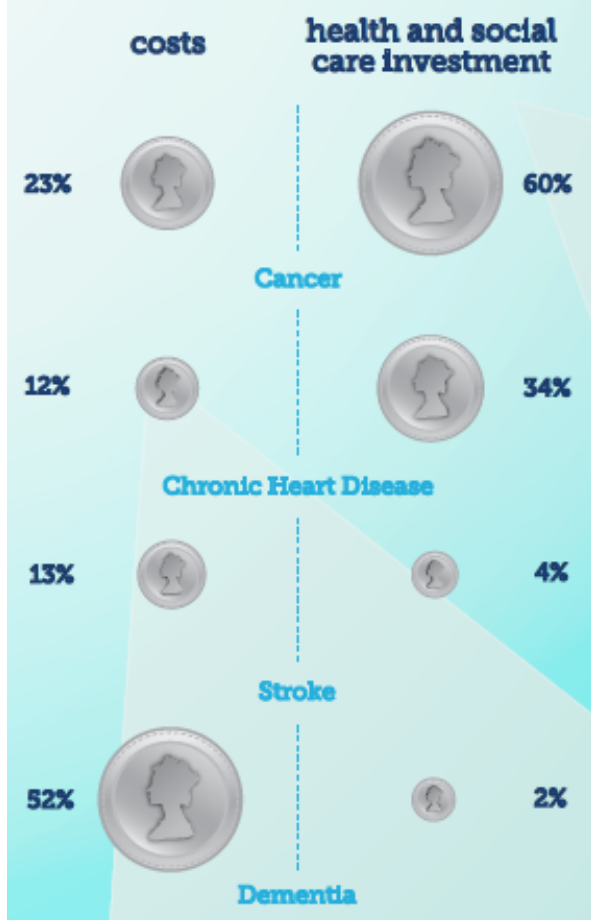
Key Points:

- It is perhaps the case that those diseases that are relatively more common in the older population, including dementia and strokes, are relatively under-funded because they are associated with old age. (Dr Luengo-Fernandez)
- As we have a ring-fenced NHS budget, the cost of the best support for people with dementia is coming out of the non-ringfenced budget, and the more-at-risk-social care budget. The NHS will be expected to divert some of that money to other areas. This risks moving people from well-supported social care support into much more costly and inappropriate hospital care. (Jeremy Hughes)
- Although the UK contributes little research funding against the overall economic cost, looking internationally it contributes significantly more than other countries. The UK contributes nearly half of all funding directed towards dementia research in Europe, compared to 12% from Germany. (Dr Luengo-Fernandez)
- There is good evidence to show that the return on investment for dementia research would be very high. (Dr Luengo-Fernandez)
- All countries, both industrialised and developing, need to invest in dementia, which is not easy, especially in the process of a developing nation's growth, when there are other huge priorities. (Baroness Greengross)

¹² The economic cost and research funding of dementia compared with other diseases, Ramón Luengo-Fernández, University of Oxford HERC

¹³ The economic cost and research funding of dementia compared with other diseases, Ramón Luengo-Fernández, University of Oxford HERC

Cost vs. research investment in four major diseases¹⁰



Comments:

"We were talking a lot about outcomes and I think that's important - what is an outcome? what is important? ... lots of quality of life stuff is very hard to measure."

unnamed event delegate in Scotland, from Alzheimer's UK

"It's going to be incredibly expensive in the future and we need someone to properly do the sums and calculate the risks [...] the evidence isn't strong yet and more research needs to be done"

Professor June Andrews via audio interview.

HIDDEN CARER COSTS

The impact on carers themselves brings significant costs, as yet unaccounted for - from stress and ill health to unpaid pensions and productivity losses.

The Statistics:

- There are 6 million carers in the UK, who save the country £87 billion a year. Of that, 14% comes from carers of people with dementia.¹⁴
- Unpaid carers make up 55% of all dementia costs; of the £23 billion that dementia cost the UK in 2008, £12.4 billion is attributed to the cost of unpaid carers.¹⁵
- By 2037, the number of carers needed overall will rise by 3.1 million.¹⁶

Key Points - from Emily Holzhausen, Carers UK:

- Those who provide 20+ hours of care per week are significantly more likely to leave their job, or go part-time. This begins to affect the individual's ability to contribute to their pension, and raises the question as to how we will make up the shortfall.
- Ceasing work early may precipitate a carer being in poverty for the rest of their life, and additional associated costs to the state.
- One research question we could address: of those carers who give up work, what is the proportion who are caring for people with dementia?
- Carers who provide 50+ hours of care per week double their risk of poor health, through the impact of stress and interrupted sleep; so bringing additional medical costs.
- We will reach a tipping point in 2017, when demand for family carers will begin to outstrip the number of people who are available to provide that care.

Comments:

"My mother has 24 hour care which costs £65,000 a year to run. That's ludicrous [...] My own time away from work has been just incredible dealing with these problems."

London event delegate, Open University Professor of Finance whose mother has dementia

¹⁴ Statistic given by Emily Holzhausen, Carers UK, taken from data from 2007. This figure has now been updated, showing the care provided is worth £119 billion

¹⁵ The economic cost and research funding of dementia compared with other diseases, Ramón Luengo-Fernández, University of Oxford HERC

¹⁶ Statistic given by Emily Holzhausen, Carers UK

“It’s not a question of just relying on their sympathy or their compassion or their love. It has to be proper retribution [sic.] for the time that they spend.”

Jose Iparraguirre, Chief Economist, Age UK

To watch this interview
press play:



“A carer will often be dealing with maybe 1, 2 or 3 different consultants at the hospital, the GP, the practice nurse, the pharmacy, different drug regimes. And then there’s the Local Authority, the Council Tax department, possibly housing benefit, maybe different aids and adaptations locally, there’s the benefits department, it just goes on and on. Can you imagine the number of appointments, the number of forms, the complications if something goes wrong? [...] Just that administration is extraordinary”

Emily Holzhausen, Carers UK, via video interview

THE HUMANITARIAN COSTS

Though we often discuss the economic and social care costs, it may be the humanitarian costs which are taking us towards crisis point.

Key Points - from Emily Holzhausen, Carers UK:

- We need to understand the impact of emotional costs for those caring for family members: for example, dealing with challenging behaviour, managing the stress of juggling work and care, and ultimately, losing the person you love.
- These costs are particularly chronic for the 'sandwich generation': those who are looking after their young children on the one hand, and their parents on the other.
- It is particularly difficult because the sense of love and community and family connections are still strong in this country. Do you give up work to care for the person you love or do you continue to try and support your family? Families are getting squeezed more and more.
- The cycle of risk is that this pressure will force more family breakdowns, and also possibly reduce the levels of care in the family.
- If families break up, we may see more single carers, or individuals living further away and caring for family members at a distance. Those who remarry may then have even more sets of parents. How do people handle care in these situations?
- Supporting individuals and families with caring responsibilities is therefore incredibly important.

Comments:

To listen to this interview press play:



“When I go to look after my mother, I’m not competent because when she falls over I haven’t been trained on how to pick her up. Now again that would be an obvious thing, if somebody in the family has dementia you should train the family members on how to deal with emergency issues.”

London event delegate, Professor of Finance, Open University, whose mother has dementia

PRIORITY THEMES

THE CONTEXT

Dementia is about people. If we are to look at transforming the system, innovation needs to correlate with the sorts of transitions and journeys experienced by the individuals with dementia, their carers and their families.

*“You can still spend a lot of money making lives better for people with dementia, we can spend it in many different ways, it’s not just about spending money to try and cure the disease.” **Dr Ramon Luengo-Fernandez***

Overall Context:

- Our National Dementia Strategy attempts an outcomes-based implementation plan, focussing on five key areas: early diagnosis and intervention, hospital care, care homes, reduction in anti-psychotics and support for carers. (Professor Burns)
- Overall, our approach needs to think about the transitions people go through - it is a journey and people who are paid to provide care often don’t understand this. (Professor Andrews)
- The three transitions begin with the point of diagnosis, which often takes place in terrible circumstances such as by letter or in a hospital corridor. The second is the point of institutionalisation, which again is hugely traumatic for families who have to make the decision to move their loved one into residential care. And the third is the point at which the person dies. (Professor Andrews)
- In considering these transitions, we need to think about route by which people get to a care home, which often comes after a hospital admission. For example, some people live in a community where the hospital is the first port of call in an emergency. The member of staff making decisions on whether to admit patients is often junior, needs to act quickly, and from an insurance point of view, it makes sense for the hospital to keep a patient in. Following this they may be at higher risk of moving into a long-term care setting. (Professor Andrews)

Comments:

To listen to this interview press play:



“The money needs to flow down differently, and there needs to be quite a lot more work done on economic modelling to look at that in relation to the stages of dementia that people can be at - we need to look at different sorts of families where people are living on their own, where families are living with a spouse who’s the same age also has support needs...the data is out there and I’m not sure we’re using the data properly to inform policy”

Jan Killeen, Director of Policy, Alzheimer Scotland

EARLY DIAGNOSIS

It is important that diagnosis rates are improved: by accessing hard-to-reach communities, by challenging the stigma of dementia by GPs and families, and by providing timely advice and support.

The Statistics:

- Only 40% of people with dementia are being diagnosed. If this doesn't improve, there will be 1/2 million people undiagnosed in 10 years.¹⁷
- Within this, there are startling regional variations. In Dorset PCT only 26% of people with dementia get diagnosed in a timely way. In Belfast 69% are diagnosed.¹⁸

Key Points:

- People who have dementia and who remain undiagnosed are costing the state money, for example, through GP visits. (Professor Andrews)
- A lack of early diagnosis may derive from individuals themselves who do not come forward through stigma and fear. (Professor Burns)
- Diagnosis brings significant repercussions for the individual and how they perceive their future life to be. They are capitulated from having a 'senior moment' to a diagnosis of dementia. Anecdotally, people say that they are concerned diagnosis would bring isolation from their community, and a withdrawal of their rights. (Professor Andrews)
- It may be the case that some GPs have 'Therapeutic Nihilism', in which they do not believe dementia is different from the general consequences of ageing. (Professor Burns)
- One woman went to her GP four times over a year before she received a diagnosis. This was given as though a full-stop, and the GP provided no signposting regarding post-diagnosis support. It was by accident that she found out about the Alzheimer's Society. (Jeremy Hughes)

¹⁷ statistic given by Jeremy Hughes, Alzheimer's Society

¹⁸ statistic given by Jeremy Hughes, Alzheimer's Society

- To support higher diagnosis rates, financial incentives are being introduced for GPs to put patients on the Dementia Register. Scotland is set to exceed its target by 30%. (Professor Andrews)
- It is a fallacy to say that nothing can be done for dementia once you are diagnosed. In clinical terms, there are treatments that have a great effect on alleviating the symptoms. A diagnosis allows a social response, too, by enabling people to plan their future, their financial and legal future, and to live well. (Jeremy Hughes)
- However, though early diagnosis is one of the core features of many government dementia policies, we do not know as yet if it improves outcomes. Much of the existing evidence is low-level, and you cannot run a randomised trial on diagnosis and see what difference that makes. (Professor Prince)
- What is very important is making a diagnosis well, by preparing a person and their families, by giving them the right information at the right time, and by making a realistic offer of help and support that will continue through their lifetime. (Professor Prince)
- Early diagnosis also means greater scope for early intervention, which can delay admission to residential care for up to two to four years. Just one post-diagnostic worker could support fifty families across a year, and in order to fund this, you would only need to delay an individual's admission to care for two to four weeks. (Henry Simmons)

Comments:

"I know a lot of elderly people realise they're having issues with memory loss but don't know how to differentiate that from general ageing....there could be better awareness across the board, maybe for the elderly people themselves, not just for the carers"

Alise Kirtley, LifeBook

To listen to this interview press play:



"Getting a diagnosis as early as possible is best for the person who may or may not have dementia and his or her family. So they can plan, so they can get the medication that is best for him or her, get any other conditions they may have assessed properly so plans can be made for the rest of their lives essentially'.

Dr Susanne Sorensen, Head of Research, Alzheimer's Society

"Diagnosis also so important to ensure clinical trials are targeted at the people who stand to benefit most #dementiacosts" (from @BoboLives)

"More stories of poor GP attitudes. GP commissioning the answer?" (from @TomPolicy)

CARE MODELS

Do we need to take more risks in care provision, by getting behind personalisation, individual budgets and tailored care?

Key Points:

- With dementia, the need for really good, suitable, tailored care, grows along with the numbers. It really must happen - not only formal care but informal care. (Baroness Greengross)
- We must allow risk, otherwise we can limit the lives of individuals significantly. What is needed is proper guidance on managing risks, to allow individuals with dementia to be as free as possible to live the lives they want. The Department of Health is looking at providing risk guidance for commissioners. (Professor Burns)
- One important change would be to promote single-points of contact. A typical scenario: as a liaison psychiatrist looking after those aged 65 + with dementia in hospital, their patient will get discharged from care, and it becomes impossible to find them and bring them back into the community team afterwards. They are being discharged because there isn't capacity for providing continued care. Investment in key workers, who integrate the process of support and care over a long period, is beneficial not only for the person suffering from dementia, but their carer. (Professor Prince)
- Personalisation and individual budgets are the key levers that we need to pull in order to cope with the changing nature of the society we live in. If every person were supported in this way, we could have a very different system in five years. We need to get people interested in personalisation and the economics of care - such as joint outcomes. It needs strong, ministerial support, so that it becomes something individuals opt out of rather than opt into. To date, we have failed to convince front-line staff they need to embrace it. (Henry Simmons)
- There are also very interesting models in Japan, such as small homes with four to six people living in with a relatively high staff ratio, in residential areas of town. As a fiscal driver for this, Japan is the only country with a truly sustainable Pay As You Go care insurance programme - we need to do this elsewhere. (Professor Prince)
- The Big Society could be a good umbrella for the existing work that communities are doing, but it doesn't come for free and it needs investment. (Jeremy Hughes)

Comments:

To listen to this interview press play:



“The GPs, if they’re now going to be the commissioning agents, should be organising groups of people to self-help or to visit each other. Because for example, my mother has 24 hour care which costs £65,000 a year to run. That’s ludicrous. These people could manage 2 or 3 people. We could have day care with dementia just as you have nursery care with children - 2 or 3 people in the same house, being looked after by a carer. They would have a fantastic quality of life and it would cost a third of the price”

London event delegate, Professor of Finance, Open University, whose mother has dementia

To listen to this interview press play:



“What came over is that care can be designed to support the individual... It’s not going to be delivered in the conventional ways that we’ve always associated with NHS and social services, there’s going to be a lot more creativity needed, but I think that playing with the full bag of clubs as it were, including the treatments coming along, the redesign of social care, I think there’s a lot that might well be done”

Phil Atkinson, Health Policy Journalist

HOLISTIC APPROACHES

If we are to be serious about patient-centred care, we need to design joined-up support and integrate choice, dignity and empowerment into all health and social care plans.

Key Points:

- We must rework the traditional model of social work and care, so that we stop managing, and return to working with families and individuals with dementia. For example, on average, three days of day care (approximately 15 hours) will cost circa £150. Even though that is a reasonable sum, there are many supportive alternatives that money could fund (for example community based groups, or activities to support active lifestyles such as allotments). (Henry Simmons)
- Those that are closest to the community should be involved not only in provisional diagnosis, but in providing continual care, connected with our wider social services. (Professor Prince)
- Rather than blaming GPs, we could better inform them on the value of non-clinical, as well as clinical obligations. We could be encouraging GPs to see they have a holistic responsibility. It's not just about prescribing medication. (Jeremy Hughes)
- Kent County Council's work on 'Total Place' is an example of how health and social care could be joined-up effectively, for example the Fire Brigade are trained to offer rudimentary health checks at the same time as checking smoke alarms in homes. (Jeremy Hughes)
- Our new Health and Wellbeing Boards should provide the opportunity to grow these holistic models because they incentivise health and social care to work together. (Professor Burns)

Comments:

"When someone has a long-term condition like dementia which is affecting every part of their everyday living, people need to be helped to cope themselves, and families need to be helped to cope with adapting to everyday challenges. We need to think much more about how we do that, rather than always- 'how do we sort out what's going wrong in hospitals or in care homes?"

Andrew Chidgey, Head of Policy and Public Affairs, Alzheimer's Society

“Dignity issues are still the real tough nut to crack. Talking about it in relation to solutions would be my wish...we’ve spent a lot of time defining issues such a dignity and privacy and respect and human rights but we’re still stalling in making a really big impact nationally.”

Tom Gentry, Policy Adviser - Health Services, Age UK

RETHINKING SUPPORT

The real transformation in dementia care comes from supporting people to remain at home for as long as possible, by empowering families through informal networks, information, choice and technology.

Key Points:

- Few hospitals have mandatory training for people with dementia, according to The Royal College of Psychiatrists' 2010 report. (Professor Burns)
- It is important that no-one suffering from dementia feels a sense of isolation or emotional trauma. Just having training to talk about it with others makes a difference. People need time. (Henry Simmons)
- In a recent study of people with dementia, 50% said they weren't receiving enough support. And 83% said staying at home was important.¹⁹
- We must therefore transform our thinking on what care is best, and there are several things we can do to sustain people in their own communities and homes. We need to recognise that some people do live in good accommodation and supportive environments. (Henry Simmons)
- Some examples: access to early intervention support is key. In Scotland there is a need for a network of dedicated post diagnostic teams, linked into GPs at the point of diagnosis. We could also develop personal plans, to guide people in their support that they and their family choose. (Henry Simmons)
- And developing the potential of networked-care, the Department of Health has funded dementia advisors to facilitate peer-to-peer support. (Professor Burns)
- The impact of technology is also critical, not just in providing health care and helping people to stay in touch, but in providing flexible solutions and to empower people with information and research. We must also remember that technology can also help to relieve stress on families and carers. (Emily Holzhausen)

¹⁹ Quoted from Professor Alistair Burns

PREVENTION

Though preventative measures and healthy lifestyle habits are thought to play a role in minimizing the risk of dementia, we continue to lack evidence to demonstrate a direct correlation with the onset of dementia.

Key Points:

- Observational studies show that people who have risk-factors for cardiovascular disease are also at quite high risk of developing vascular dementia. We could posit that improvements in cardiovascular health feed through the system to bring reductions in instances of dementia as well. (Professor Prince)
- Yet our problem is that trials on preventative factors to date have been conducted with people in their 60s and 70s when it is arguably too late to understand their impact. At this age, the development of dementia may already be in motion. (Professor Prince)
- We should see good nutrition and exercise as making a positive impact for those already with dementia, not just as prevention. (Professor Andrews)
- It is important to look at health expectancy as well as life-expectancy. Studies in the USA support the compression of morbidity - meaning the years of life we are gaining are for the most part healthy. This effect has not been demonstrated for dementia as we do not currently have the data to look at it. (Professor Prince)
- One question posed was: is the onset of dementia still at the same approximate age in the past, or as we live longer, is the onset of dementia being delayed? Do we spend more of our lives living with it?

Comments:

“If people can take actions that actually delay the onset of dementia for say five years, it gives the individual five years of better life, or better health, but it could also make a significant difference to the public purse.”

Head of Research, Alzheimer Scotland

“I would want to be cautious about not scaring our population that dementia is almost inevitable, that’s something I feel quite strongly about.”

Maureen O’Neill, Director, Faith in Older People

WHERE NEXT?

SUMMARY OF RECOMMENDATIONS

Technology

Increase the role of technology to support patient choice and independence, and to support carers and families.

Behaviour Change and Advocacy

Launch a UK-wide awareness campaign to address stigma and misinformation.

Actively involve and enable many more people with dementia to choose their own care options and be politically involved.

Continue to promote the benefits of early diagnosis within the medical profession, particularly GPs.

Research

Conduct more research on preventative healthcare in relation to the onset of dementia.

Develop more comprehensive data collection to support cost analysis on dementia, especially statistics on the number of carers who are caring for people with dementia.

Support

Attach a value to caring thorough training, support and skills.

Develop commissioning packs giving guidance to Primary Care staff and GP Consortia about what a good service involves.

Provide GPs with metrics 'dashboards' so they can review patient information in a more comparative way through metrics.

Give GPs guidance on referrals to memory assessment services so they can get people diagnosed early.

Increase training on dementia support for hospital staff.

Financing

Release more of the healthcare budget to support the social care budget.

Impress on co-commissioners the importance of total costs, in the long term, and how to make sustainable use of available funds.

Care Models

Develop the case for personalisation.

Explore insurance models such as pay-as-you-go.

Promote the role of key-workers as single points of contact for individuals with dementia and their families.

Harness the potential in GP consortia to enable self-organised care on a local level.

Comments:

“Do we actually need to get people to collectively invest in insurance for longterm care, separately from what we do now, if we’re going to be serious about affording different ways of doing it?”

Maureen O’Neill, Director, Faith in Older People

“I see a real change, a real enthusiasm, a real energy for people that I meet around the country, interested in changing the services and the provision of care for people with dementia. It’s that impact, it’s that engagement, it’s that ownership of the challenge of dementia which for me is the thing that is very exciting.”

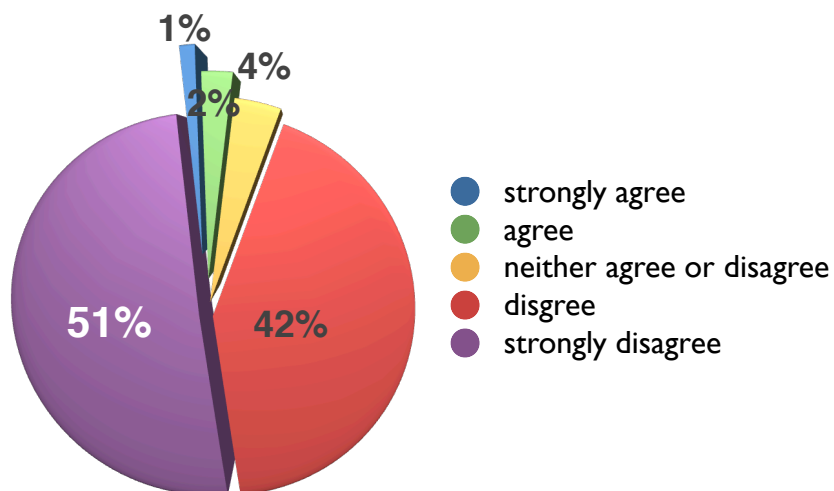
Professor Alastair Burns

VOTING RESULTS

Results from live voting at the London event :

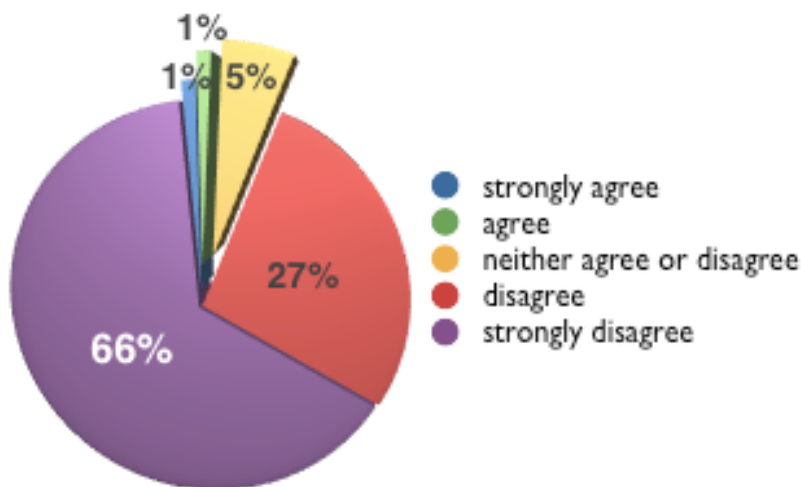
By 2020 nearly a million people will be living with dementia.

Do you think as a society we are ready for the increase in the number of people with dementia?



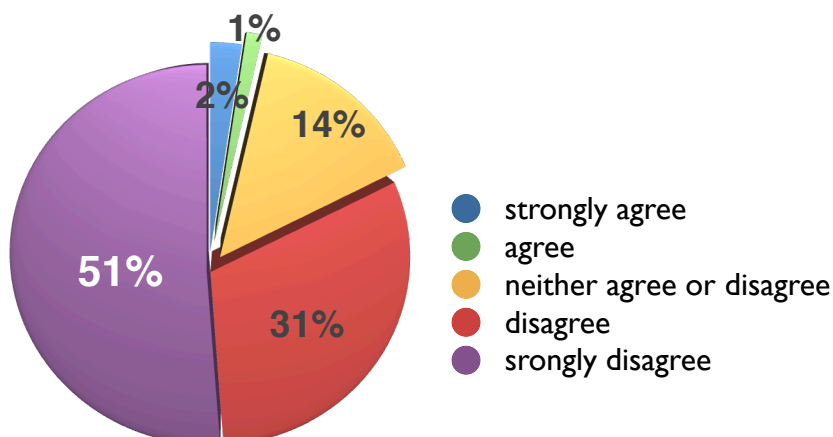
By 2020 nearly a million people will be living with dementia.

Do you think the Government is prepared in terms of long-term strategies to respond to the increase in the number of people with dementia?



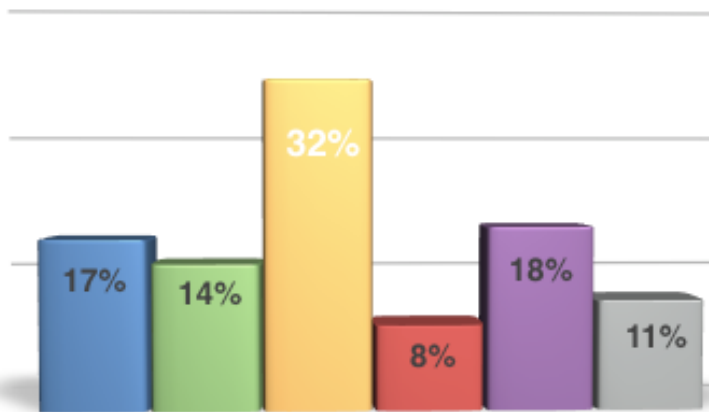
To what extent do you agree with the following statement:

“Government funding of dementia research is at an adequate level”

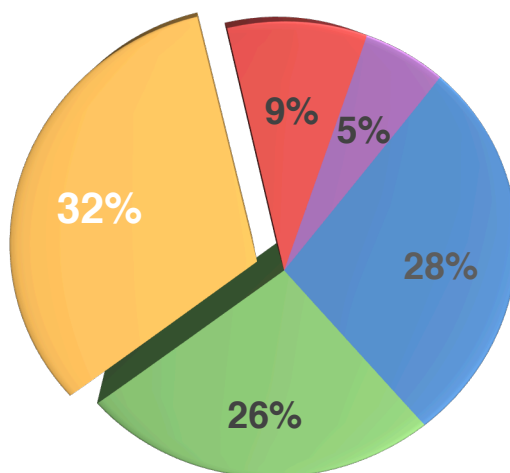


Which of the areas below, do you consider is most in need of additional Government funding?

- Preventative health
- Early diagnosis
- Effective support and services
- Residential care
- Support for carers
- Dementia research

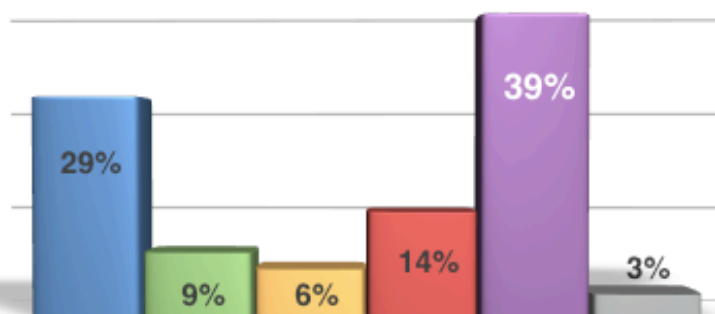


Is preventative healthcare cost-effective for older people, particularly with regard to dementia?



- Strongly agree
- agree
- neither agree or disagree
- disagree
- strongly disagree

Should policy change to respond to the role of unpaid carers and where should the priority lie?



- Yes – carers should receive greater financial support from the benefits and tax systems
- Yes – carers should be paid the equivalent market rate
- Yes – carers should receive vouchers from employers to pay for care
- Yes – the care and support system should be reformed within current funding
- Yes – the care and support system should be reformed with additional funding
- No – the status quo should remain

VIDEOS AND LINKS

To watch videos with the speakers from the London event go to: <http://www.youtube.com/user/dementiacosts>



Interview with Professor Alistair Burns; National Clinical Director for Dementia, Department of Health, Professor of Old Age Psychiatry, University of Manchester

<http://www.youtube.com/watch?v=ekM9ZJ0OmFU>



Interview with Emily Holzhausen; Director of Policy and Public Affairs, Carers UK

<http://www.youtube.com/watch?v=QGpBKiaU9Ss>



Interview with Dr Ramon Luengo-Fernandez; Senior Researcher, Health Economics Research Centre, Department of Public Health, University of Oxford

<http://www.youtube.com/watch?v=DiG-lgjU52U>

REFERENCE LINKS

Links to all reports mentioned by speakers:

10/66 Dementia Research Group - <http://www.alz.co.uk/1066>

Acute Awareness, NHS confederation - <http://bit.ly/b4UgQu>

Alzheimer's Research Trust: Dementia 2010 - <http://www.dementia2010.org/>

Carers UK: Facts about caring - <http://www.carersuk.org/Newsandcampaigns/Media/Factsaboutcaring>

Counting the Cost, Alzheimers Society - <http://bit.ly/bDTSjB>

Dementia 2010: The prevalence, economic cost and research funding compared with other major diseases, Ramon Luengo-Fernandez, Jose Leal, and Alastair Gray (2010) - <http://www.herc.ox.ac.uk/pubs/bibliography/dementia2010>

Dementia care in hospitals: Findings from National Audit of Dementia interim report, the Royal College of Psychiatrists - <http://www.rcpsych.ac.uk/press/pressreleases2010/nadinterimreport.aspx>

Dementia prevalence and diagnosis rates map, The Alzheimer's Society, Alzheimer's Scotland & Tesco - <http://www.alzheimers.org.uk/dementiamap>

Dilnott Commission - <http://www.dilnotcommission.dh.gov.uk/>

Global prevalence of dementia: a Delphi consensus study, The Lancet, Dec 2005 - <http://www.thelancet.com/journals/lancet/article/PIIS0140673605678890/abstract>

Mental health and wellbeing in later life, Healthy Ageing Programme, NHS Health Scotland - <http://www.healthscotland.com/topics/stages/healthy-ageing/mental-health-later-life.aspx>

Mental health Gap Action Programme (mhGAP), World Health Organisation - http://www.who.int/mental_health/mhGAP/en/

National Dementia Strategy - <http://www.dh.gov.uk/en/SocialCare/NationalDementiaStrategy/index.htm>

'Nothing Ventured Nothing Gained- risk guidance for people with dementia', Department of Health - http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_121492

Quality outcomes for people with dementia: Building on the work of the National Dementia Strategy, Department of Health - http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_119827

Support. Stay. Save. Care and support for people with dementia in their own homes - economic model, Alzheimer's Society - http://alzheimers.org.uk/site/scripts/download_info.php?fileID=1032

The Rising Cost of Dementia in the UK, Alzheimer's Society http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=342

The Mid Staffordshire NHS Foundation Trust Public Inquiry - <http://www.midstaffspublicinquiry.com/>

World Alzheimer Report, Alzheimers Disease International - <http://www.alz.co.uk/research/worldreport/>