

The Dementia Challenge

In August 2007, the then Labour Government announced a programme to develop the first National Dementia Strategy and implementation plan for England (1). Following an immense amount of hard work and a public consultation process, in 2009, the Labour government produced a strategy for providing a strategic framework within which local services could deliver quality improvements to dementia services and address health inequalities relating to dementia; provide advice and guidance and support for health and social care commissioners and providers in the planning, development and monitoring of services; and provide a guide to the content of high-quality services for dementia. (1) The Government gave dementia a 'national priority'. The publication of the first National Dementia Strategy under Alan Johnson, Secretary of State for Health aimed at achieving the goal of building health and social services for dementia fit for the 21st century.

The Strategy outlined three key steps to improve the quality of life for people with dementia and their carers:-

- First, to ensure better knowledge about dementia and remove the stigma that sadly surrounds it, which was similar in many ways to the stigma that cancer used to carry in the past. Many people in the NHS and social care come into contact with people with dementia and their carers. They needed to know more about dementia and how they can best provide care that meets people's needs.
- Second, to ensure that people with dementia were properly diagnosed. Current best estimates were that only one-third of people with dementia ever received a diagnosis of their illness. Some argued in the past that it is best not to let people know. This has long been accepted that this should not occur with cancer sufferers. The same should be true for those with dementia.
- Third, to develop a range of services for people with dementia and their carers which fully meets their changing needs over time.

This first-ever national dementia strategy, to be implemented over a 5 year period to 2014, to transform the care of the rising number of sufferers and their families, was launched with a funding of £150m and the promise of a string of memory clinics and advisors across the country. However, it was criticised for failing to deliver on two crucial issues – research into the causes and potential treatments of dementia and the drugging of elderly people in care homes. A review of antipsychotic drugs used in care homes to sedate people whose dementia makes them angry or distressed was postponed until later (2). Nonetheless, the government's claim that the strategy was a "landmark" in the care and treatment of people with dementia in England was endorsed by dementia experts and patient groups who had long campaigned for a comprehensive plan of action.

The National Dementia strategy highlighted the needs and service provision for people with dementia and their carers. There was a good sense of reality within the document, with direct quotes from people with dementia and their carers, reflecting a range of opinions and attitudes to the current services provision. Key issues of concern are openly stated and addressed. Such areas include:-

- The 'stigma' attached to dementia, and the need for a publicity campaign to address this.
- The need for early diagnosis and intervention to improve quality of life and prevent crises
- The number of people admitted to care homes in instances where this may not be necessary
- The importance of all health and social care services to be appropriate for use by people with dementia, through appropriate training of staff and provision of personalised services
- The inappropriate use of anti-psychotic medication to control behavioural and psychological symptoms, when other non-pharmacological management approaches could be used
- Analgesia and pain management for people with dementia, particularly for those nearing the end of life.

Implementation of the strategy led to 94% of primary care trusts establishing a memory service for dementia, organisations from health, social care and the voluntary and commercial sectors forming the Dementia Action Alliance and the launch of the dementia commissioning pack. This provided a set of tools and templates for health and local authority commissioners, helping them to design services that are suited to local needs and are cost

effective. It supported planning across the whole spectrum of dementia, from early diagnosis to end of life care, together with guidance on how to reduce the inappropriate use of antipsychotic medication. The commissioning pack consisted of a set of materials to help commissioners in health and social care commission better services for people with dementia and their carers. It was developed in consultation with a range of health and social care experts, including people with dementia and their carers and was aimed to:-

- Improve quality of services for people with dementia by placing patient outcomes and patient choice at the heart of the commissioning process
- Drive efficiency by reducing unwarranted variation in services
- Reduce bureaucracy for commissioners by providing tailored documents and templates, bringing together the different aspects of commissioning (clinical, financial, commercial, contractual and procurement)

On 8 September 2010, the Department of Health published a revised, outcomes-focused implementation plan for the National Dementia Strategy (NDS). Quality outcomes for people with dementia: building on the work of the National Dementia Strategy updates the previous implementation plan for the Strategy (which was published in July 2009) and aimed at accelerating the pace of improvement through a greater focus on local delivery and local accountability and empowering citizens to hold local organisations to account. The implementation plan set out the Department's four priority objectives for securing improvements in dementia care, which were:-

- good quality early diagnosis and intervention for all;
- improved quality of care in general hospitals;
- living well with dementia at home and in care homes;
- reduced use of anti-psychotic medication.

Improving outcomes for carers underpins each of these priority areas. The evidence in this Action Plan was grouped in line with the four priority areas for securing improvements in dementia care set out above. In October 2010, the Department of Health announced the development of a further commissioning pack for dementia which was published on 21 July 2011 (3). The commissioning pack consisted of a set of materials to help commissioners in health and social care commission better services for people with dementia and their carers. The pack covered the four priority areas in the 2010 National Dementia Strategy implementation plan ; Good quality early diagnosis and interventions; Better care in hospitals; Better care at home and in care homes and Reduced use of anti-psychotic medication. In relation to the National Dementia Strategy as a whole, people with dementia, their carers and families, would be expected to benefit through better awareness of dementia, early diagnosis, good quality information and high quality care and treatment at all stages of the illness and in all settings. The public would benefit from the National Dementia Strategy through improved public awareness and understanding of dementia.

Dementia affects people from all backgrounds and with a wide range of protected characteristics. People with dementia can suffer from stigma and discrimination and difficulties in accessing services. In particular, the challenge of living well with dementia could be significant for people also living with other medical conditions. The implementation of the National Dementia Strategy should mean that all people with dementia and those who care for them, regardless of their background, would have access to the best possible healthcare and support. The Department of Health considers the overall impact of both the implementation of the Strategy and the commissioning pack to be a positive one.

The Dementia Challenge was launched in March 2012 by Prime Minister, David Cameron (4) to deliver major improvements in dementia care and research by 2015. The Dementia Challenge work programme superseded the national strategy and focuses on 3 main areas: (a) bringing about improvements in health and care, (b) creating dementia friendly communities and (c) improving research. He said that...." *dementia is one of the biggest challenges we face today – and it is one that we as a society simply cannot afford to ignore any longer. We have made some good progress over the last few years, but there's still a long way to go. Our research knowledge on dementia lags behind other major diseases such as cancer or heart disease. People with dementia and their carers still face a lack of understanding from public services, businesses and society as a whole. And as many as half of all dementia sufferers in*

this country are unaware that they have the condition, meaning that they cannot get the help that they and their families need. So I am determined that we will go further and faster on dementia – making life better for people with dementia and their carers, and supporting the research that will ultimately help us slow, stop and even prevent the condition. Of course the Government doesn't have all the answers, and we can't fix everything overnight. But with a sustained and concerted effort from all parts of society, I believe we can make a real difference – and we are determined to do so."

Three years on from 2009, progress was summarised as:-

- 94% of primary care trusts (PCTs) having a dedicated memory service for dementia.
- The NHS and Social Care had taken forward initiatives to reduce the prescribing of antipsychotic drugs.
- More than 90 leading organisations joined the Dementia Action Alliance (DAA) since October 2010. Organisations from health, social care, and the voluntary and commercial sectors were working together to help improve the quality of life for people with dementia, their carers and families.
- A Dementia Commissioning Pack was launched in July 2011, to guide NHS commissioners in getting the best possible outcomes for people with dementia and the best value for money.

Future key commitments were outlined in the Challenge as follows:-

a) Driving improvements in Health and Care:-

- Increased diagnosis rates through existing checks for over-65s
- Financial rewards for hospitals offering quality dementia care
- An Innovation Challenge Prize of £1m NHS staff
- A Dementia Care and Support Compact signed by leading care home and home care providers
- Promote local information on dementia services
- Work with the profession to identify how best to improve early diagnosis of dementia through improvements in awareness, education and training
- Requesting NICE to consider ways of improving the dementia
- The NHS will guarantee a written integrated personalised care plan to people with dementia.
- There will be better support for carers
- Carers should have the right to be assessed and their needs met
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b) Creating Dementia Friendly Communities that understand how to help:-

- Support from leading businesses for the PM's Challenge on Dementia.
- Awareness-raising campaign.
- Work with the Alzheimer's Society to develop local Dementia Action Alliances to bring together people with dementia, their carers and key organisations.
- Make sure that people with dementia and carers on diagnosis have an information pack about dementia produced in conjunction with the Alzheimer's Society.
- The Dementia-friendly Communities Programme working in partnership with the Dementia Action Alliance.

c) Better Research:-

- More than doubling overall funding for dementia research to over £66m by 2015.
- Major investment in brain scanning.
- £13m funding for social science research on dementia (NIHR/ESRC)
- £36m funding over 5 years for a new NIHR dementia translational research collaboration to pull discoveries into real benefits for patients.
- Participation in high-quality research.

- The MRC will spend over £3m in supporting the UK brain bank network, which connects all the UK brain banks for the benefit of donors, researchers and future patients.
- A major event to be staged for pharmaceutical and biotech companies to showcase the benefits of conducting dementia research in the UK,
- Work towards recruiting 10% of patients into clinical trials.
- Up to £9m of DoH funding will be made available for research into 'living well with dementia' and the delivery of dementia care.
- The DoH will increase its support for capacity-building in dementia research, focusing on nurses as well as doctors.

In May 2013, a report was issued detailing progress (5) to date under the 3 main themes:-

1. Driving improvements in health and care:-

- By 2015, the NHS aim is that two-thirds of people should have a diagnosis, with appropriate post diagnosis support.
- An Enhanced Service for take up by GPs for having a pro-active, case finding approach to the assessment of patients who may be showing the early signs of dementia.
- The Government's response to Dilnot and the reforms to the social care system once implemented in 2016. (only likely to make a difference for a small minority)
- Public Health England has named dementia as one of its seven high level priorities for in recognition of the key role public health can play in the delivery of better dementia care and support.
- The launch of a 'Dementia Care and Support Compact' with major care providers to improve care and support for people with dementia living at home and in care homes.
- Establishing the Commissioning for Quality and Innovation (CQUIN) reward for hospitals offering dementia risk-assessments to all over-75s admitted to hospital as an emergency.
- Dementia friendly hospitals working in partnership with their local Dementia Action Alliance.
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2) Creating dementia friendly communities that understand how to help:-

- The Dementia Friends programme run by Alzheimer's Society aims to increase awareness and understanding of dementia by educating 1 million people to become 'Dementia Friends' by 2015
- Over 50 cities, towns and villages taking local action to become dementia friendly.
- Alzheimer's Society working in partnership with the Dementia Action Alliance to establish local dementia action alliances across the country. Over 20 Local Dementia Action Alliances have been established bringing together organisations to take responsibility
- A dementia education pioneer programme was launched with 21 schools across the country testing different approaches to educating children and young people about dementia.
- Delivering a nationwide campaign to raise awareness of dementia and to encourage people to visit their doctor if they are worried about dementia.

3) Better research:-

- Major expansion of the neuroscience programmes at the world-leading Medical Research Council (MRC) Laboratory of Molecular Biology (LMB). Resources have been increased by 50 percent with a major part dedicated to research on dementia and neurodegeneration.
- Provision of over £22 million of additional funding through the National Institute for Health Research (NIHR).
- The Economic and Social Research Council (ESRC) and the Department of Health, launched a call in July 2012 to fund up to £13 million social science research proposals in preventing dementia.
- £9.6million provided by the MRC for a pilot study involving 8,000 volunteers as the first phase of a brain imaging programme that will ultimately scan the brains of 100,000 Biobank participants.

One thing is clear: the Prime Minister's Challenge on Dementia has created a new momentum in health and social care, research and across society as a whole to do more to help and support people with dementia, their carers and families, a focused approach to delivering improvements.

It was an historic moment in December 2013, when the UK used its chair of the G8 (G7) for a summit in London for Global Action against Dementia (GAAD). Leaders from around the world made commitments to innovate, invest and collaborate towards finding a cure for dementia. The G8 (G7) signed up to a shared vision to identify a cure or disease modifying therapy by 2025 and to embrace international collaboration on dementia through a series of high level actions set out in a Declaration and Communiqué (6) This innovative step, from David Cameron and Jeremy Hunt, to initiate and involve the whole of the world in a global action on such a serious health issue, will probably rate as one of the best accomplishments of the Coalition. At the summit, the G8 (G7) Countries made a commitment to work together to improve the quality of life for people with dementia and their carers, with an ambition to identify a cure or a disease modifying therapy by 2025. Implicit in this (now) G7 action was a commitment to progress their own dementia strategies and to accelerate the science, innovation and research that each had underway.

Addressing the Summit, David Cameron said *"it is about 3 things: realism, determination, and hope. Realism – because no-one here is in any doubt about the scale of the dementia crisis. It doesn't matter whether you're in London or Los Angeles, in rural India or urban Japan - this disease steals lives; it wrecks families; it breaks hearts and that is why all of us here are so utterly determined to beat it. We meet with determination too. In generations past, the world came together to take on the great killers. We stood against malaria, cancer, HIV and AIDS and we are just as resolute today. I want December 11 2013 to go down as the day that the global fight-back began. Not just on finding a cure for dementia but preventing it, delaying it, and critically – helping those who live with dementia to live well, and live with dignity. We've got some really ambitious objectives - to increase funding, to share data – but frankly we have got to be ambitious if we want to beat this. We've got to turn that determination into something real. And we meet here with hope. The debate on dementia can get pretty defeatist. Of course – the challenge is huge. And yes – we're a long way from a cure. But there is hope. And I see hope in this room – some of the most respected scientists, thinkers and politicians from around the world, coming together to beat this. We meet in the country where Watson and Crick unravelled DNA... where genetic fingerprinting, the MRI scan and the beta blocker were invented. We meet with the conviction that human ingenuity can overcome the most daunting of challenges. We meet with the determination that we will take the fight to dementia – and help improve or save millions of lives."*

The G8 Health Ministers in their declaration stated *"We recognise that dementia is not a normal part of ageing. It is a condition that impairs the cognitive brain functions of memory, language, perception and thought and which interferes significantly with the ability to maintain the activities of daily living. We also acknowledge that dementia affects more than 35 million people worldwide, a number that is expected to almost double every 20 years. We note the socio-economic impact of dementia globally. Seventy per cent of the estimated annual world-wide cost of US\$604 billion is spent on informal, social and direct medical care. Yet nearly 60 per cent of people with dementia live in low and middle income countries so the economic challenge will intensify as life expectancy increases across the globe. These costs are expected to increase significantly if therapies to prevent dementia and improve care and treatment are not developed and implemented. We recognise the need to strengthen efforts to stimulate and harness innovation and to catalyse investment at the global level."*

In accordance with national, sub-national and local responsibilities, they committed to 12 principles for combined global action against dementia. In November 2014 at a meeting with regulators it was stated (Raj Long)that *"The one thing that we can't have is business as usual if we want to make a real difference for people with dementia and their families. Regulators must now come together as a group and look at dementia, and see what can be done to find innovative solutions to the problem "* As a result, six areas of priority action were identified by the regulators including an appetite to widen multilateral cooperation internationally, underpinned by series of regulator-led projects including. In March 2015 (7) the G7 was provided with an independent assessment of the global approach to the development of safe, effective and affordable medicines for dementia by 2025 and included a set of recommendations for governments, regulators and industry.

The Dementia Platform UK (DPUK) was announced in June 2014, and is a £53 million industry-partnered programme, funded by Medical Research Council with £4 million provided through six industry partners from the biopharma sector, along with eight universities. The partners collectively will deliver the world's largest research cohort, of two million study participants who have supplied detailed biological, clinical and lifestyle information for research, supplemented by the creation of three national technology networks, spanning neuroimaging, disease modelling and informatics.

A recent progress report summarises what has been achieved so far as regards the 12 G8 commitments (7). Some research findings since 2013 are as follows:-

- By studying the prescription records of nearly 9000 older people living in Quebec suggests a link between the use of benzodiazepine drugs and increased risk of developing Alzheimer's disease. 1796 of the people studied had a diagnosis of Alzheimer's disease, and of these, nearly 50 per cent had been given benzodiazepines in the last five to 10 years prior to their diagnosis. This study demonstrated a link between benzodiazepines, which are commonly prescribed to treat anxiety and sleep disturbance, and Alzheimer's disease – although a limitation of this study is that benzodiazepines treat symptoms such as anxiety and sleep disturbance, which may also be early indicators of Alzheimer's disease. (8)
- A study published in September 2014 found that aromatic turmerone, a compound found in the plant turmeric, can boost the generation of stem cells in the brains of rats. Researchers looked at the effect of turmerone on cells within the brain that can become nerve cells. These neural stem cells generate the growth of new nerve cells, so can play a role in helping the brain to repair damage. This treatment is now being explored to determine whether it has any potential for neurodegenerative diseases. (9) The use of turmeric as a memory enhancer is not new.....see Drugs section.
- Another study looked at drugs used for type-2 diabetes to stave off symptoms of Alzheimer's Disease. Early results of the study show that those taking the pioglitazone medication for type 2 diabetes were at less risk of developing dementia.
- A Sleep Study in individuals with mild cognitive impairment and dementia demonstrated that sleep disturbances show high prevalence in mild cognitive impairment and dementia patients, and they are often associated to each other. Poor sleep results in an increased risk of morbidities and mortality in dementia patients.(10)
- Researchers have found that levels of copper in the bloodstream may be able to indicate Alzheimer's disease in its earliest stages. A study tested blood samples from older people with mild cognitive impairment, and compared levels of copper to results from memory tests conducted every six months. After four years, researchers found that 50 per cent of those people with the highest level of free copper in their blood had developed Alzheimer's disease. Conversely, less than 20 per cent of those with the lowest levels of free copper had developed the disease four years later, which suggests that lowering copper intake could help reduce risk.(11)
- In a 2014 study of volunteers with the rare, familial early-onset form of Alzheimer's, researchers previously identified biomarkers showed an unexpected pattern of change over time. The goal of the study was to understand how cerebrospinal fluid (CSF) biomarkers change as the disease progressed. The researchers' first analyzed CSF biomarkers, beta-amyloid levels, and the cognitive status of volunteers: 146 carried the mutant gene for early-onset Alzheimer's and 96 were non-carriers. As had been found in previous studies, among the younger participants, those with the mutation had biomarkers that indicated disease onset some 10 to 20 years before symptoms are expected to show. These markers included reduced CSF beta-amyloid 42 levels (associated with increased amyloid plaques), increased levels of CSF tau (associated with tau tangles), and other markers associated with damaged neurons, including a new marker called visinin-like protein-1 (VILIP-1).
- One team from the University of California studied the effects of young blood on the production of new neurons, or neurogenesis, in the brains of older mice. Neurogenesis normally tapers off during aging, as does blood flow to brain regions where new neurons are born. They found blood from young mice stimulated blood vessel growth in these brain regions of aged mice, doubling blood flow to the area. The researchers were able to partially mimic the effects of young blood on vascular growth and neurogenesis by treating aged mice with GDF11, a blood protein that promotes the growth of several cell types (12). Many molecules

are present at higher levels in the blood of young people compared to older people, and this and other related studies suggest that some of those molecules could be useful therapeutic targets.

- In January 2015 the MRC Toxicology Unit provided evidence that neurodegenerative diseases can be halted in animal models by subverting mechanisms that have a normal function in hibernation, offering an entirely new therapeutic target for Alzheimer's (13). The research team discovered that a "cold-shock" chemical called RBM3 could be used these to prevent brain cells dying in animals, providing a potential new drug target. The study suggested that RBM3 was key to the formation of new neuronal connections and in a series of tests showed the brain cell deaths from prion disease and Alzheimer's could be prevented by artificially boosting RBM3 levels.

There is growing evidence that links modifiable risk factors such as physical inactivity, poor diet and smoking with dementia. From the Blackfriars Consensus (14) on promoting brain health and reducing risks for dementia in the population, the general public, health professionals and policy makers are increasingly aware of the links between behavioural risk factors and non-communicable diseases (such as tobacco and lung cancer or diet and cardiovascular disease). But few people are aware that many of the same risk factors could impact on the risk of dementia. It is therefore important to communicate more clearly the emerging evidence about dementia risks, protective factors and preventive actions to the public and relevant health and care professionals and policy makers. However, the emerging evidence suggests that the risk of developing dementia can be reduced but it cannot be eliminated.

The case for a risk reduction approach was further endorsed by Johns (15) at the WHO/UK conference on dementia in Geneva March 2015, that physical activity and the management of cardiovascular risk reduces the risk of cognitive decline. The evidence is perfectly consistent with the factors known to reduce the risk of cancer, coronary heart disease, diabetes etc. In a Finnish geriatric intervention study (16) to prevent cognitive decline (FINGER study), a large, long-term, randomised controlled trial, showed for the first time that lifestyle changes could improve or maintain cognitive functioning in at-risk elderly people from the general population. Participants in the trial had not yet developed substantial memory problems but were thought to be at risk of cognitive decline.

As a last report in this Parliament, David Cameron issued a summary of what has been achieved so far together with the challenge to 2020 (17), setting out the areas where the government believes it will be necessary for society to take sustained action in order to deliver this vision and to truly transform dementia care, support and research by 2020. People want hope for the future, to know that real progress is being made towards preventing and treating dementia, and that there is a global effort to find a cure. By 2020, it is his hope that England will be the best country in the world for dementia care and support and for people with dementia, their carers and families to live and the best place in the world to undertake research into dementia and other neurodegenerative diseases.

It is to be hoped that the next government will continue and properly fund this work.

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