

DINNER/DISCUSSION SUMMARY

An ageing population: meeting the challenge of caring for the
rising number of dementia patients

Held at The Royal Society on 3rd October, 2012

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ESRC/NIHR Dementia: prevention, intervention and care initiative,
IXICO and the Wellcome Trust

Chair: **The Earl of Selborne GBE FRS**
Chairman, The Foundation for Science and Technology

Speakers: **Professor Dame Sally Davies DBE FMedSci**
Chief Medical Officer, Director General of Research
and Development, and Chief Scientific Adviser, Department of Health
Professor Julianne Meyer
Professor of Nursing: Care for Older People and
Director of the My Home Life Programme, City University
Professor James Goodwin
Head of Research, Age UK
Jan Hall OBE
Founder Member, The Evington Initiative

DAME SALLY DAVIES outlined the scale of the problem of dementia, and the size of the challenge in meeting it. 600,000 patients in England now suffered from dementia; in 10 years it will be 1,000,000. 1 in 3 over people who are 65 now will develop it. But the great stigma that attaches to it, and ignorance about it, exists not only in the public, but also in the medical and caring professions. Health carers, including GPs often do not know about it, or even understand it. It is not a synonym for Alzheimers; it may often stem from cardio-vascular problems, which can be dealt with differently. GPs, patients and relations often feel that a diagnosis of dementia is a death sentence, and therefore, do not care to make it, or have patients who accept it when given. But early diagnosis can extend good quality life for a longer period and enable patients and carers to plan for the future. In 2009 only 42% of cases were diagnosed early; and only 31% of GPs (with significant regional variation) have sufficient training to diagnose effectively. The Prime Minister's dementia challenge¹ published in March, 2012 sets out a view of how to make the UK a world leader in care and research. The Dementia Awareness campaign is directed to increasing awareness and understanding in specific sectors, such as financial services, schools, transport and retail. Action was also being undertaken to improve care in hospitals,

the training of doctors, to understand the implications of life care and to support carers. But further action was needed to unlock the vast data base available in the NHS, to use life science research to focus on the problem and to ensure research findings are transferred to clinical and therapeutic use. We must treat dementia as a crisis affecting all sectors of society. We cannot accept the present and forecast scenario as acceptable. All parts of society need to be involved - the NHS and caring professions cannot deal with it on their own. Key to this is the involvement of the community as a whole; it is the community which needs to understand dementia, accept it as something all might eventually suffer, help those suffering and relieve the pressure on those, whether at home or in care homes, who are caring for sufferers. This is not just a matter for the state and charities.

PROFESSOR JULIENNE MEYER said her aim was to promote better health care for those in care homes. There were 400,000 people in care homes with an average age of 85 and 66% with Mild Cognitive Impairment (MCI). 60% die in care homes. They have a high degree of dependency and are unprepared for their condition. Care homes are seen as "islands of the old". Above all they need to be better connected to the community and work in partnership with it. People often have a negative view of care homes – "money grabbing" or "poor quality". The My Home Life Programme, of which Professor Meyer is one of the Directors, works with the Government's commitment, to involve communities, to

¹Prime Minister's "Dementia Challenge"
www.number10.gov.uk/news/dementia-challenge

improve social care and in particular, to improve the quality of life for those in care homes. "Quality of life" must cover all those living and dying, visiting and caring for those in care homes. The interdependence of community and care homes is crucial. Support for the My Home Life Programme work must be evidence based, relation centred, appreciative of the work needed and being done, and make a genuine difference to care. We must break down the silos of health and social care. Old people want to be able to retain individuality, links with the past and connections with life around them. They also need to feel safe, and see a purpose in life. We need to recognise that care managers feel often great stress, and concern that the system matters more than the patient. The key words for the future were *trust* (between carers and cared, and homes and communities); *enable* (having the knowledge and tools to improve quality of life); *network* (ensure all know this is a problem for all) *support* (understand the pressure on carers); and *empower* (the patient as well as those caring).

PROFESSOR JAMES GOODWIN said his basic aim was to take research through to practice by effective knowledge transfer. He outlined the present and future scenarios. Today we have 820,000 people living with dementia. 1 in 20 over 65 and 1 in 5 over 80 suffer from dementia. But many more have MCI – 16% at 65; and MCI leads to increasing risk of dementia. By 2051 it is forecast that there could be 1,735,000 dementia sufferers. Current costs of dementia (including loss of productivity) were £23bn annually; globally \$604bn. The aim was to reduce projected increase rates by half. Research shows that 24% of changes in cognitive ability are genetic; that changes in white matter in the brain affects cognitive ability and that physical activity is good for cognitive activity. We also know that cardio vascular effects are important and we know that higher risks of dementia are associated with life styles – hypertension, cholesterolmic excess, obesity – together they increase risk by a factor of six. The transfer of research into practice is complex. It depends on culture and trust. Does the researcher understand the problems on the ground? Is the practitioner willing to accept and use research findings? Knowledge and priorities in the pharmaceutical industry are also relevant. But the pressure is there – the national strategy on dementia, the Ministerial summit on dementia, the Ministerial advisory body, the mention in the coalition programmer and the PM's challenge all help to highlight the issues. However, the current spend on R&D on dementia was inadequate. The total spend on all R&D in 2010 by all sectors was £26,362 million of which £7,350 million was on health; £590 million on cancer; £169 million on heart disease; but only £50 million on dementia research. "Push" efforts

were to get research out to practitioners; get research output embodied in treatment; grow research capacity; harness existing resources and information and engage the public. "Pull" factors were the engagement of charities, better training of doctors and carers, and the increasing engagement of the public. In short, there was slow but steady progress on research, better training, more public awareness and better understanding on means of knowledge transfer. But there was much to do.

MRS HALL gave a moving account of what it was like to be in a family where a member suffered from Alzheimers. She recounted the effect of her mother's illness on her father, herself, her brother and her children. Her father had been forced to watch his wife appear to go into a day dream and no longer be his partner. He suffered the stress and difficulty of dealing with her increasing physical inabilities, and the social isolation that followed, as their friends did not want to know of the problems. Her terror of change and of getting into an ambulance were described. She and her brother had to consider what they would do if their father could no longer cope. Her mother would not acknowledge she had Alzheimer's and hospitals did not recognise her problems of fear and incomprehension of what was happening to her. It was like a toddler desperately needing to cling to her mother's skirts. Research must be pressed for a cure, and the biggest step must be through encouraging the pharmaceutical industry to concentrate more effort on the search for new and effective drugs.

A principal focus in the following discussion was the need to help the carers of those who were living at home. The pressures could be well nigh intolerable, as Mrs. Hall had illustrated, and the limited assistance from social care (leaving those who had already incurred £22,500 expenditure without resources from the state) and the difficulty of getting the patient accepted in a hospital, or in a care home, were insufficiently recognized. Moreover, the cost the state incurred in patients going into either a hospital or care home was much greater than that incurred in home care. Much of the problem was the social isolation that carers as well as the sufferers endured; dementia carried a powerful stigma; people did not wish to know about it or be associated with it. It is prejudice. Age UK and other charities were working both to persuade the government to fund home care adequately and to educate the public about dementia and Alzheimer. How often did one see a young disabled person being given care, which would stimulate and encourage him or her, while a dementia patient would be left alone? This was discriminatory and raised issues about Human Rights. The vital lesson was that the greatest factor in dementia is age, and we all age. More needed to be done to give carers clear guidance about how to act and help as the

patient becomes increasingly helpless. There are ways of making life more bearable for carers by helping them understand the sufferer's mind (comparison with the fears of toddlers for example), the likelihood of depression, often inevitable with dementia, and what is best practice for carrying out manual tasks.

Better use of technology can help – but many carers need help in understanding technology or web based guidance. But, carers are often old themselves and find on-line help difficult to access. Caring raises, political, social and personal issues, which interact.

Speakers were concerned about the scope and direction of research. It was important to understand that aging was a very complex subject and that we did not yet understand well how diseases, such as dementia, associated with aging develop. We don't know how or why neurones die. We should not talk about cures, but about how to modify the effects of the disease. It was difficult to balance the long and short term research efforts. There is a strong need to help people overcome immediate problems, but this must not obscure the need for long term research which may hold out hope for the future. The research capacity was still too low, and there were gaps in all sectors, but it was growing. A crucial area was research to understand how scientific findings could be used more effectively by practitioners.

Speakers referred to the commitment to enable sufferers "to be confident that my end of life wishes will be respected". Did this mean that, if an advance directive had been signed, it would, with proper safeguards, be respected if the sufferer had indicated he wished to die if he was imposing burdens on others, or lacked a quality of life he wanted? Some speakers thought this was not relevant to the debate, but others thought that quality of life involved being able to be confident about such choices. It was true that one could not necessarily judge how a dementia sufferer felt about the quality of his life, but it was the impact of dementia on spouses and carers that mattered too many and that they wished to see avoided. Quality of life covered much more than quality of care, and more than the quality of life of the patient.

Speakers raised concerns about conditions in hospitals, as well as care homes. The problem was that hospitals were built for acute cases, and not primarily for long term care. Their designs were out of date for present circumstances and were not suitable for long term dementia patients, which they were obliged to accept. Nor did the staff in them have the right training to deal sympathetically with such cases. The NHS had initiatives both to improve

care in hospitals and, importantly, to involve the public, but it would take time. Patient, rather than the system, must be the centre of care.

Three areas of particular concern emerged from the discussion:

First, the issue of stigma and the involvement of the community in understanding dementia and helping those with it, and those caring for them in care homes or at home. Until the stigma attached to dementia was lessened, people would still shun sufferers and fail to understand the pressure on carers. Much more effort should be devoted to this issue.

Second, while more research and research capacity was needed, it must be well directed, in particular to ensuring it transfers to patients, and balances long and short term issues. Be wary of hoping for cures; we do not yet have the basic knowledge to find these; but improve early diagnosis and mitigate effects.

Third, improvement of quality of life for sufferers, carers and all who are associated with dementia patients must be the aim. This goes much wider than better care; it means understanding what is the purpose of life for an individual, how to bring him into relationship with the past and with those he or she knows. Better training of doctors, nurses and carers is important.

Sir Geoffrey Chipperfield KCB

Useful web links:

Academy of Medical Sciences
www.acmedsci.ac.uk

Age UK
www.ageuk.org.uk

Alzheimer's Disease International (ADI): Overcoming the stigma of dementia
www.alz.co.uk/research/world-report-2012

Alzheimer's Society
www.alzheimers.org.uk

Cambridge Cognition
www.camcog.com

Economic and Social Research Council
www.esrc.ac.uk

ESRC/NIHR Dementia: prevention, intervention and care initiative
www.esrc.ac.uk/funding-and-guidance/funding-opportunities/21219/dementia_initiative.aspx

The Evington Initiative
www.theevingtoninitiative.org

The Foundation for Science and Technology
www.foundation.org.uk

My Home Life Programme
www.myhomelife.org.uk

IXICO
www.ixico.com

Medical Research Council
www.mrc.ac.uk

National Institute for Health Research
www.nihr.ac.uk

NHS
www.nhs.uk

Prime Minister's "Dementia Challenge"
www.number10.gov.uk/news/dementia-challenge

Professor Julianne Meyer
www.city.ac.uk/health/staff-directory/professor-julienne-meyer

Technology Strategy Board – Tomorrow Together
Campaign
<https://tomorrowtogether.innovateuk.org/>

The Royal Society
www.royalsociety.org

The Wellcome Trust
www.wellcome.ac.uk

World Health Organisation (WHO) report on Dementia
– A Public Health Priority.
www.alz.co.uk/WHO-dementia-report

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