



MAKING THE CASE

FOR THE SOCIAL SCIENCES

NO.11 DEMENTIA

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Foreword

Dementia is the major challenge of our time for health and social care. It is impossible to ignore the global demographic imperative in terms both of numbers of people affected (rising from 46.8 million in 2015 to 74.7 million in 2030) and costs (approx £575 billion in 2015 – over 1% of global GDP).¹ The Prime Minister's Challenge on Dementia (2012-2015 and 2015-2020) makes clear that increasing the quantity and quality of dementia research is a priority for the UK government. Mr Cameron's aspiration is for our country to be "the best place in the world to undertake research into dementia and other neurodegenerative diseases". The UK has taken a global lead in the 'fight to defeat dementia', through initiatives from the G7 countries, the EU Joint Programme on Neurodegeneration and the World Health Organisation. Nevertheless, although funding for dementia research has doubled, the total figure is still very low compared to other conditions such as cancer.

Dementia is the umbrella term for a number of conditions all resulting in a loss of abilities, relating to memory, orientation, reasoning, judgement and self-care. Alzheimer's disease is the most common type, followed by vascular dementia and Lewy Body dementia. Many people live with a dementia in their 40s and 50s, but the dementias are most common in later life, when a person may develop a mix of the various conditions.

Most attention is usually given to biomedical research in this field. Important though this is, dementia cannot be seen only through a biomedical lens. The human consequences for people living with a dementia and for those who provide care and support need to be a focus of study and action. This booklet provides striking examples of how social scientists in the UK are already making headway with this agenda. Dementia care across the world has been transformed by some of the advances in understanding and in care and treatment evidenced here.

¹ Figures from Alzheimer's Disease International's World Alzheimer Report 2015. Originally shown as US\$818 billion.

For example, the near universal adoption of person-centred care has improved the lives of many people living with dementia worldwide. This stemmed from the work of social scientists at the University of Bradford, recognised in 2015 by a Queen's Anniversary Prize for Higher and Further Education. Indeed, the UK is a world leader in psychosocial interventions in dementia care and in taking action on the rights of people with dementia.

Researchers received a great boost through the 2012 Economic and Social Research Council/National Institute for Health Research dementia-themed call awarding £20 million to 6 major projects over a 5 year period, which will build further impact in due course, and from the newly developing Medical Research Council-led National Dementia Research Institute announced in November 2015. It is vital that funding for social science research on dementia increases. The work reflected here could then be the platform for even greater impact in years to come.

This issue has been made possible through the kind support provided by the British Psychological Society, Alzheimer's Society, Age UK, the School of Dementia Studies at the University of Bradford and the British Society of Gerontology.



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Professor Roger Goodman FAcSS
Chair, Academy of Social Sciences



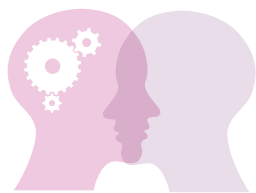
A handwritten signature in black ink, appearing to read 'James Wilsdon'.

Professor James Wilsdon FAcSS
Chair, Campaign for Social Science



A handwritten signature in black ink, appearing to read 'Jamie Hacker Hughes'.

Professor Jamie Hacker Hughes FBPSS
President, British Psychological Society



Person-centred care and dementia care mapping: setting the standard and training the workforce

Training an informed workforce to provide quality health and social care for the growing number of people living with dementia is a top priority for UK and international governments.

First developed at the University of Bradford by Professor Tom Kitwood, Person Centred Care (PCC) emphasises the importance of providing care which addresses the psychological and social aspects of living with dementia in order to ensure wellbeing. PCC is now a widely used term in the UK and internationally and is synonymous with the transformation of health and social care for people living with dementia and their families. Now led by **Professor Murna Downs**, the team at the University of Bradford have developed a suite of training in Person-Centred Care for the NHS and social care workforce, including major long term and domiciliary care providers. This has involved an empowering programme of train-the-trainer approaches including developing bespoke work books suitable for different care settings. The person-centred approach has now been embedded in Health Education England's online modules:

Introduction to person-centred care and Advanced practice in person-centred care.

The University's Doctoral Training Centre in Transitions in Dementia Care, funded by the Alzheimer's Society, ensures the development of future leaders in person-centred care research.

Recognising that much training fails to be embedded within everyday practice, Kitwood developed an observational tool and PCC practice development methodology called Dementia Care Mapping (DCM). DCM provides professionals and practitioners with a language with which to record the experience of care from the perspective of the person with dementia as well as an evidence-based approach to action planning to improve that care.

A cluster trial conducted in Australia showed decreases in falls and agitation in care homes that used DCM and using it has also been shown to benefit staff morale and practice.



The National Institute for Health and Care Excellence (NICE) recommends DCM as an approach to practice development and the National Audit Office recommends it as a measure of quality of life. The University of Bradford has trained more than 4,000 practitioners in its use and has partnerships with organisation in more than 10 countries to deliver training in the method.

With the Care Quality Commission, a team at the University of Bradford developed the Short Observation Framework for Inspection, a derivative of DCM. This is used by inspectorates in England, Wales, Scotland, Australia and the Netherlands to capture the experience of people using services who may not be able to express themselves verbally.

<http://www.bradford.ac.uk/health/dementia/>

<http://www.e-lfh.org.uk/programmes/dementia/>



Improving skilled care means less medication

It is estimated that as few as 36,000 of the 180,000 people with dementia prescribed antipsychotics in the UK actually receive any benefit from them, while inappropriate prescribing leads to up to 1,800 extra deaths each year.

Much of this medication is given to people living in care homes, so it is important that care homes have the necessary skills and knowledge to deliver good quality care without excess sedation.

Based on research funded by the Big Lottery and conducted by **Professors Ballard and Howard at King's College London** with **Dr Jane Fossey of the University of Oxford** and **Oxford Health Foundation NHS Trust** and **Dr Ian James of Newcastle University**, the FITS (Focussed Intervention Training and Support) programme was developed to enable care home staff to deliver effective care for people with dementia in place of inappropriate medication, providing instead

person-centred approaches and evidenced-based psychosocial interventions.

The researchers ran a cluster randomised controlled trial and found that using the FITS programme meant a 40% reduction in prescribing of antipsychotics for people with dementia. They published a manual for practice and provided the basis for much of the advice in the Alzheimer's Society Guidance (2011) on helping people with Behavioural and Psychological Symptoms of Dementia. The findings also influenced the development of the British Psychological Society guidance on alternatives to antipsychotic medication.





Alzheimer's Society subsequently funded the researchers to work with **Professor Dawn Brooker and her team at the University of Worcester** to develop the FITS into Practice Programme to deliver the programme across a large number of care homes. Staff designated as Dementia Care Coaches (DCCs), who were responsible for implementing interventions in 1 or 2 care homes, participated in an in depth ten-day education course in person-centred care over a three-month period, followed by 6 supervision sessions.

The researchers evaluated the interventions by monitoring prescriptions of anti-psychotic drugs, knowledge, attitudes and how well the techniques were being implemented. They also produced some case studies and looked at reflective journals kept by some of those taking part.

Participants demonstrated better knowledge and improved attitudes to dementia, resulting in 31% less inappropriate anti-psychotic prescribing.

The National Institute for Health Research (NIHR) funded the Oxford and King's College London teams to optimise and update the FITS methods in two randomised control trials (WHELD study). The initial findings show a 50% reduction in prescribing and a 36% reduction in mortality for those people who received a combined package of drug review and social intervention. As a result the 2011 Alzheimer's Society guidelines have been revised and new ones will be available in 2016.

<https://www.alzheimers.org.uk/FITS>

<http://ajp.psychiatryonline.org/doi/full/10.1176/appi.ajp.2015.15010130>



'Nothing ventured, nothing gained': risk management for people with dementia

We all face risk in our lives and regularly make judgements about the risks and benefits of our everyday actions. People with dementia often find their opportunities to make these decisions are restricted because of overly cautious approaches to risk. **Professor Jill Manthorpe FAcSS and Jo Moriarty of the Social Care Workforce Research Unit at King's College London** were asked by the Department of Health to produce guidance based on published research that could be used by health, social care and housing professionals, families, and people with dementia.

A summary of the available research showed that people with dementia, family members, and health and social care practitioners often had different ideas about risk. While some topics, such as driving or financial abuse, had been comparatively well researched, there was less material about other situations such as deciding if it was safe to leave a person with dementia on their own in the house.

The researchers also discussed the problem with people interested in the topic, including other researchers, practitioners, policymakers, family carers, and people with dementia. From this the research team produced a simple 'heat map' based on balancing the contribution a particular action could make to individuals' quality of life against its risk of causing harm or reducing their quality of life.

The research programme resulted in Department of Health guidance: *'Nothing Ventured, Nothing Gained': Risk Guidance for people with dementia*, with associated training packages, including adaptation for people with a learning disability living in care homes or supported living. The guidance is formally supported by various organisations, including the Alzheimer's Society, the British Association of Social Workers and the Royal College of Nursing, and extracts are widely used in local protocols for risk enablement.



The ethics of dementia care

Is it ever right to restrain a person with dementia who might otherwise wander? Or to hide medication in food? Family carers may face difficult ethical dilemmas on a daily basis. Despite a strong and growing body of social science that could inform these dilemmas, little has been developed into advice or guidance.

The Nuffield Council on Bioethics convened a working party with a broad range of multidisciplinary expertise, including in the social sciences. Over two years it synthesised research, gathered evidence and tested ideas through 'fact-finding' meetings and visits involving a variety of institutions including academic departments, care homes and 'dementia cafés'. An open consultation in 2008 received over 200 responses and a deliberative workshop gauged the opinions of 50 members of the public.

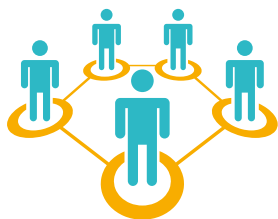
In 2009 the findings fed into a Council report, *Dementia: Ethical Issues*, which presented an ethical framework to help people think through issues that emerge in dementia care, and concluded that people can live well with dementia if they are properly supported.

The report recommended that narrowly-conceived risk assessments that restrict people's activities should be replaced with analyses of risk and benefit, and this was cited approvingly in the 2010 Department of Health guidance, *Nothing Ventured, Nothing Gained*, which condemned 'an overly cautious approach to risk'.

The Council report's emphasis on the importance of 'dementia friendly communities' emerged as an important theme in the *Prime Minister's Challenge on Dementia* and was cited in the Irish Government's national strategy in 2014. Further policy support featured in a 2013 report by Alzheimer Europe, which recommended ways that people with dementia could be supported to continue living their lives as fully as possible.

From the national strategies of Scotland and Malta to publications by Alzheimer's Australia and charity coalitions in Wales, the report's recommendations continue to reverberate.

<http://nuffieldbioethics.org/project/dementia/>



Life story work

A person's life story – the experiences, relationships, joys and sorrows – is the core of their identity.

Dementia challenges the continuity and coherence of the person's own account, so it is essential that those providing care and support have a good understanding and knowledge of the person's life story in order to provide care that is person-centred.

Professor Bob Woods FAcSS and his team at the Dementia Services Development Centre at Bangor University carried out research which looked at how life story work helps preserve a person's identity and, in doing this, enhances the level of care they receive. In one care home study, life story books – which simply told the story of who they had been, what they had enjoyed doing, who their family and friends were - clearly helped improve both the quality of life and also the autobiographical memory of the person with dementia, as well as leading to staff knowing the person

better and reporting more positive attitudes to dementia. Further, relatives reported an improvement in their relationship with the person with dementia, finding the book made visiting a more positive experience.

This research has now been widely adopted using a variety of media, including digital apps as well as conventional books.

The Department of Health funded the Life Story Network to train over 500 health and social care staff, family carers and volunteers in life story work, arising from the national dementia strategy.

Organisations such as the Social Care Institute of Excellence (SCIE), major charities including Dementia UK and Alzheimer's Society, and professional organisations such as the Royal College of Nursing (RCN)

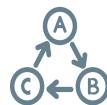


have also promoted the approach as good practice. A joint Alzheimer's Society / RCN brief life story template 'This is Me' is used in general hospital wards across the country to help staff quickly get to know the person and their preferences, contributing to person-centred care for thousands of people with dementia.

See: <http://www.iriss.org.uk/sites/default/files/iriss-insight-4.pdf>

<http://www.scie.org.uk/dementia/after-diagnosis/knowning-the-person/get-to-know-me.asp>





Making decisions; taking action

Making decisions and being safe are some of the fundamental worries for people with dementia and their carers. People fear that they will lose the rights to make decisions but also they fear that they will not be looked after well and that their vulnerabilities will make them open to exploitation and abuse. These worries are shared by family carers.

Professor Jill Manthorpe FAcSS and Dr Kritika Samsi at the Social Care Workforce Research Unit at King's College London

carried out research to track the changes being brought about by the Mental Capacity Act 2005 and how it is affecting people with dementia, their family carers and care providers. This was part of a larger research programme investigating evidence based interventions in dementia (EVIDEM).

They concentrated on ordinary or everyday decisions – made by family members and frontline professionals – which are often overlooked.

This includes new rights to appoint decision makers and to make decisions in advance. Many older people interviewed welcomed these new rights but some preferred to rely on the doctors they knew or their family to make important decisions.





The researchers explored how this law also potentially helps people with dementia have greater access to justice since it established a new criminal offence to ill-treat or neglect a person lacking decision-making ability. They found that few cases have been prosecuted but generally professionals welcomed this. Another linked study, with Lynne Phair, found that many hospital staff were woefully uninformed about the Act as training and information had not been a priority.

There were mixed pictures in other settings too, but adult safeguarding practitioners were generally the best informed.

The team built on their earlier work compiling accessible national training materials for the Act. Research provided a way of benchmarking the changes in practice. Organisations such as the Social Care Institute of Excellence (SCIE), Dementia UK, Alzheimer's Society, the British Association of Social Workers, Community Care Inform,

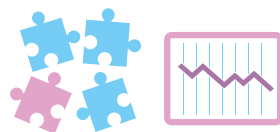
and Making Research Count, use the findings in face to face training, online resources, and professional practice to promote good practice and share information. This includes informing the contents of fact-sheets so that they focus on what proved to be common questions and information needs. The team is involved with new government initiatives to refresh the Act, provides evidence to policymakers, and continues to offer training to care providers drawing on the research's findings that practitioners like 'real life' examples and being able to relate the law to themselves and their own families.

See: MCA training materials:

http://www.wales.nhs.uk/sites3/documents/744/Mental_Capacity_Act_Core_Training.pdf

Information factsheet:

https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=354



Cognitive rehabilitation

Dementia strategies worldwide emphasise the need for early diagnosis, but there has been a dearth of effective evidence-based psychosocial interventions to offer alongside the currently available medications, to enable people with early-stage dementia to live well, cope with their disability and maintain the interests and activities that they value.

Professor Linda Clare FAcSS of the University of Exeter has pioneered the application of a cognitive rehabilitation approach to meet the needs of people with early-stage dementia. Reviewing the existing literature she and her team demonstrated that cognitive training (practising a set of mental exercises) was not beneficial for people with dementia, and that a different kind of approach was needed.

She carried out some feasibility studies and was able to demonstrate that it was possible for people with early-stage dementia to achieve their goals through both compensatory strategies (such as using memory aids) and targeted new learning (e.g. how to use a mobile phone) to bring

about behaviour change. This work led to the development of an intervention in which people with dementia and their families work together with a health professional over a number of sessions to identify needs and goals relating to everyday activities, and then devise and implement strategies for achieving these goals.

This programme was tested in an initial randomised controlled trial conducted in North Wales, funded by Alzheimer's Society.

As a result of the cognitive rehabilitation intervention people with dementia had better cognition, mood and quality of life and were more successful in reaching their goals.

Carers also experienced reduced stress and better quality of life.



Data from brain scans before and after the therapy showed positive changes for the treatment group, which were interpreted as reflecting some restoration of function.

Although a larger study is underway to confirm the scale of the effects already identified, the approach has already become widely used internationally. The work is informing the International Federation on Ageing 2016 Copenhagen Summit on reablement and dementia. The summit is an international high-level knowledge exchange platform of government officials, industry leaders and civil society (<http://www.ifa-copenhagen-summit.com/about-the-copenhagen-summit/>).

The approach is recommended by both the British Psychological Society (2014) 'Guide to psychosocial interventions in dementia' and by the Royal College of Psychiatrists Memory Services National Accreditation Programme.





Extending therapies that work

Cognitive Stimulation Therapy (CST) is a well-established and important tool that improves quality of life and aspects of memory and language skills in people with mild to moderate dementia. Alzheimer's Disease International recommends that cognitive stimulation should routinely be used with people with early stage dementia, and it continues to be implemented in dementia care across the globe, most recently in Nigeria and Tanzania.

The NHS Institute for Innovation and Improvement (2011) conducted an economic analysis of alternatives to antipsychotic drugs for individuals living with dementia, focusing on the cost and benefits of providing CST.

They concluded that by combining health care cost savings and quality of life improvements, behavioural interventions generate a net benefit of nearly £54.9 million a year to the NHS.



However, CST is typically carried out in small groups which can make it difficult or impossible to access for people who are geographically isolated or who have transport or physical health problems that prevent them from joining groups. Also, research showed that some people prefer individualised interventions, and a number of family care-givers requested an approach they could use with the person with dementia at home.



Dr Aimee Spector of University College London and Professor Martin Orrell, now at the University of Nottingham,

led a research programme which worked in partnership with family care-givers and people living with dementia to improve the way CST is delivered. They developed 'Individualised CST' (iCST) which can be delivered on a one-to-one basis by family care-givers or by paid staff such as community care workers.

A study of 356 people with dementia and their care-givers living across the UK showed that people living with dementia reported an improvement in their relationship with the care-giver after taking part in iCST sessions.

Additional benefits also emerged as care-givers reported an improvement in their own quality of life.

Both people with dementia and family care-givers valued mental stimulation and people with dementia also valued activities that were meaningful and helped them keep in touch with the world around them.

A manual for family care-givers was published with input from people with dementia and care-givers which emphasised the importance of fun and enjoyment. As one participant in the iCST study living with dementia commented:

'I don't remember the activities, but I enjoyed what we were doing.'

For more information about CST visit:

<http://www.cstdementia.com/>

<http://www.ucl.ac.uk/international-cognitive-stimulation-therapy>



Helping people from minority ethnic backgrounds access services

Many people in the UK are coming forward for early diagnosis of dementia, speaking out about their lives and showing that, with the right support, it is possible to live well with dementia.

However, figures show that people from minority ethnic backgrounds still tend to access dementia services much later than the majority White population.

Dr Naaheed Mukadam, Dr Claudia Cooper, Professor Gill Livingston and colleagues at University College London set out to understand why this is the case. They interviewed family carers to find out what influenced the timing of when they sought help for their relative's dementia. Their sample included men and women from seven different self-reported ethnicities, including 'black', 'white', South Asian and Chinese.

Despite the fact that most relatives noticed memory problems, the researchers found that those from minority ethnicities delayed seeking help until they ran into severe difficulties. Some relatives attributed early problems to other causes or found it hard to persuade the person to visit the doctor. Sometimes the wider family didn't agree with them seeking outside help, or enabled or expected them to cope without help.

Help-seeking tended to be precipitated by physical illness, risk, or difficulty managing confused or distressed behaviour. Minority ethnic carers did not always find the diagnosis itself helpful but did find specialist services beneficial in providing advice, drug treatment and support.

The study has helped to push service providers to make greater efforts to raise awareness of dementia in minority ethnic populations, for example through culturally specific 'roadshows', and to tailor their services, such as Alzheimer's Society's Information Programme for South Asian Families.



Dementia costs

Rapid ageing worldwide means not only many more people with dementia, and the personal and social challenges associated, but also economic challenges for families and health and care systems.

Research by the Personal Social Services Research Unit at the London School of Economics and Political Science (LSE) has explored these economic challenges and future possibilities. One strand of work calculated treatment and support costs and projected them over future decades. Other studies examined the cost-effectiveness of interventions such as Cognitive Stimulation Therapy (CST), medications, and support for unpaid or family carers.

After the first ever international summit on dementia, organised by the G8 countries in London in 2013, the Department of Health for England commissioned further work from the LSE to feed into governmental and international discussions, including at the newly established World Dementia Council. **Professor Martin Knapp FAcSS** and his colleagues were asked to quantify

current and expected economic impacts of dementia, and to estimate costs and quality of life outcomes under different care and support scenarios.

They found that the best evidence-based interventions known today could considerably improve the lives of people with dementia and also of their unpaid carers. However this would make little difference to overall dementia costs, which would probably only be significantly reduced by slowing the progression of the underlying disease or delaying its onset, whether by medical interventions or widespread behaviour and lifestyle change.

The findings fed into development of the new national dementia policy (*Prime Minister's Challenge on Dementia 2020*), the OECD's report on dementia and care (*Addressing Dementia*), and deliberations at the first World Health Organisation Ministerial Conference on Global Action Against Dementia.



Improving public understanding of dementia



Most people don't really understand what dementia is. It is estimated that less than half of those with dementia have been formally diagnosed and low public understanding of dementia's social impact has been a significant factor in this as the condition is often misunderstood as being entirely biomedical. Early diagnosis is important to enable access to treatment, management and planning, which reduce hospital stays as well as the emotional and practical impact on families, and NHS costs.

To address the lack of public awareness, **Professor Anthea Innes and her team at the Bournemouth University Dementia Institute** collaborated with a public engagement artist, Derek Eland, and the Bournemouth Symphony Orchestra, on two action-research projects.

The first used a technique called 'diary rooms'. They exhibited hand-written responses on coloured postcards at events in England, Scotland, Malta and Puerto Rico and invited 2000 exhibition visitors to do



the same. 61% of visitors without dementia reported improved understanding of what it means to live with the condition after seeing the first-hand accounts.

Researchers asked 600 members of the public, including 100 with dementia, 'What is it like to live with dementia?' and 'What do you think dementia is?'

The second project invited people with dementia, their family members, students and volunteers to play alongside professional musicians in a series of orchestral rehearsals and performances. Analysis of weekly observation, video-recording, interviews and feedback forms showed improved understanding of dementia by students, professional musicians and audiences. There were also improvements to wellbeing for participants with dementia while engaging with the instruments and co-participants, and their relationships with their families



improved. Relatives also experienced respite and improved mood, and felt socially supported by the group. Evaluations of the six public performances showcasing the participants' achievements demonstrate that watching one performance alone has contributed to shifts in public perceptions about what living with dementia means.

By improving awareness and understanding by families and the wider public, these interventions are breaking down one of the main barriers to early diagnosis, paving the way to better outcomes for people with dementia and their families.

<https://research.bournemouth.ac.uk/engagement/budis-dont-mention-dementia-exhibition-experiences-of-dementia-told-through-art/>



Preventing dementia

The UK's Cognitive Function and Ageing Studies give us a unique insight into the number of people who may be living with dementia. The study was first carried out in the early 1990s and when it was repeated recently in 2010 by a national team led by **Professor Carol Brayne of the University of Cambridge**, the figures showed a 22% drop in the estimated number of people aged 65 or over living with age-related dementia.

The results also showed that social deprivation mattered with increased levels of dementia age for age in areas with greater social deprivation.

The results of this study are already in use by NHS England, with local systems using these up-to-date estimates to inform the government target of identifying over 60% of the estimated number of affected people in each locality.

Importantly this multidisciplinary and multi-institutional team was able to show from this work that risk for dementia at particular ages can be reduced, probably through factors across the whole of the lifecourse, including lifestyle.

Other studies have shown that many risk factors for dementia have changed across successive generations such as improved education.





Professor Marcus Richards of University College London found evidence from the British birth cohorts to show that formal schooling directly benefits cognitive function, even after allowing for the obvious fact that children of high early cognitive ability are likely to do well in school. He also found that this is equally true of adult education and training, which additionally benefits cognitive function even after taking account of formal schooling as well as prior cognitive ability. A comparison between the British 1946 and 1958 birth cohorts shows that

the influence of education on cognitive function is stronger in the younger cohort, which is almost certainly the result of the government raising the school leaving age in the intervening 12 years, resulting in a substantial increase in the proportion of children leaving school with educational qualifications.

<http://www.cfas.ac.uk/>



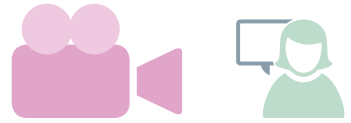
Enabling people with dementia to influence policy and practice

Ten years ago people with dementia were invisible and silenced, stereotypically perceived as incapable, and excluded from research, policy and practice.

Professor Heather Wilkinson of the University of Edinburgh led research to challenge widely-held beliefs about how far people with dementia can meaningfully participate. She showed that people with dementia have an important contribution to make to research, policy and practice, and that methodological and ethical challenges in the involvement of dementia patients in those areas can be addressed and overcome. As a result the Scottish Dementia Working Group (SDWG), which includes people with dementia, was formed in 2002 under the umbrella of Alzheimer Scotland. Professor

Wilkinson initially worked closely with James McKillop, a person with dementia, who later chaired the SDWG for six years, became a member of the Alzheimer Europe Working Group and was awarded an MBE for services to dementia.

In 2009 the SDWG partnered with the Scottish Parliament's cross-party group on Alzheimer's at the launch of the Charter of Rights for people with dementia, which led to the first Scottish Dementia Strategy in 2010. Nicola Sturgeon, then Deputy First Minister, said: "It has been vital to me that, in implementing the strategy, [Alzheimer Scotland and the Scottish Dementia Working Group] have both been at the heart of the large programme of work, providing expert advice and input on the services to which people are entitled, and influencing the implementation of the various strands of the strategy".



The SDWG has been involved in outreach to professional groups and members have contributed to training DVDs which were produced in collaboration with Health Scotland, Alzheimer Scotland and NHS Education for Scotland. Group members were also on the National Integrated Care Pathways steering group, mapping out service needs, and they continue to work closely with the Care Commission.

In these ways people with dementia are now able to directly influence and inform practice directives, guidance and frameworks at a national level.

Jean Georges, Executive Director of Alzheimer Europe, describes the SDWG as a “particularly successful example” of a campaigning group run for and by people with dementia and, in 2012 the European Dementia Working Group was launched, based on the SDWG model. In 2014 Japan launched its own Dementia Working Group after spending time with the Scottish group and making a documentary film about their work.

<http://impact.hss.ed.ac.uk/case-study/influencing-dementia-philosophy-policy-and-practice>



Measuring and improving outcomes of social care

Most care home residents have dementia. Although we hear a lot about poor care, these homes aim to improve people's quality of life, no matter how severe people's problems. However, evaluating the impact of care services on people's quality of life is important so that we can target resources where they have most effect and improve service quality.

To date, most measures of outcome have been either too focused on health or too broad to be accurate.

People with moderate or severe dementia have often been excluded from studies because they find it difficult to take part in questionnaires or interviews.

In response, **Professor Ann Netten FAcSS and Ann-Marie Towers with colleagues at the University of Kent's Personal Social Services Research Unit** developed the Adult Social Care Outcomes Toolkit (ASCOT),

for use in a variety of settings and with people with any disability. It contains a mixed-methods approach for use in care homes, including formal and informal observation as well as interviews with the resident (if possible), staff and relatives. The toolkit, which requires training, provides both a measure and important insights into care provided and 'social-care-related quality of life' of residents, including basics such as food and drink and 'higher order' aspects such as control and occupation.

In addition to providing evidence about the impact of services, ASCOT is used by central and local government and increasingly by care providers and those responsible for evaluating, monitoring and commissioning services, nationally and internationally, to improve outcomes of the people using services. Following feedback from training and users of ASCOT, a 'home level' approach is being developed, to help commissioners and care home providers focus on quality of life when reviewing how homes care for all their residents.

Other titles in the series are:

1. Wellbeing
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8. Longitudinal Studies
9. Mental Wellbeing
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The national academy of academics, learned societies and practitioners in the social sciences. The Academy's Campaign for Social Science was launched to raise the profile of social science in the public, media and Parliament.

The Academy of Social Sciences, 33 Finsbury Square, London EC2A 1AG
www.acss.org.uk | www.campaignforsocialscience.org.uk



The British Psychological Society is the learned and professional body for psychology and psychologists in the UK. It is responsible for the development, promotion and application of psychology for the public good.

www.bps.org.uk



We are the UK's leading dementia support and research charity, here for anyone affected by any form of dementia in England, Wales and Northern Ireland.

www.alzheimers.org.uk



We're Age UK and our vision is a world where everyone can love later life.

www.ageuk.org.uk



The School of Dementia Studies at the University of Bradford leads the field in dementia research, education, training and practice development.

www.bradford.ac.uk/health/dementia



A multidisciplinary forum for all those interested in the situations of older people, and knowledge about ageing and later life.

www.britishgerontology.org