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- Sensory stories
- Learning from Japan: social projects with business links
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Front cover photograph and those on p25: thanks to Kate Mansfield-Loynes, Trish Morris-Thompson, Di Marks-Marlan and all involved in this creative project.
We are excited to announce the keynote and plenary speakers appearing this year:

- **Professor Carol Brayne** is Professor of Public Health Medicine in the Department of Public Health and Primary Care at the University of Cambridge and Director of the Cambridge Institute of Public Health. A medically qualified epidemiologist and public health academic, her research focuses on public health, ageing and the brain. She will give an update on the latest research on prevention of dementia and the implications for public health.

- **Professor Alistair Burns** is Professor of Old Age Psychiatry and Vice Dean for the Faculty of Medical and Human Sciences at The University of Manchester. He is an Honorary Consultant Old Age Psychiatrist in the Manchester Mental Health and Social Care Trust (MMHSCCT) and is the National Clinical Director for Dementia, NHS England.

- **Professor Arlene Astell** is Ontario Shores Research Chair in Dementia, University of Toronto, Canada and Professor of Health Services Research in the Centre for Assistive Technology and Connected Healthcare (CATCH) at the University of Sheffield, UK. Professor Astell will give the Tom Kitwood Memorial Address, in the spirit of Kitwood’s focus on the well-being of each individual with dementia.

- **Professor Sube Banerjee** is Professor of Dementia and Associate Dean at Brighton and Sussex Medical School, and Director of its Centre for Dementia Studies. Clinically he works as an old age psychiatrist, and his research focuses on quality of life and quality of care in dementia.

- **The opening debate will ask**: should we welcome a future of robots, avatars and digital technology in dementia care?

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**7th National Dementia Care Awards 2016**
The National Dementia Care Awards are returning to UKDC this year on the 3rd November at the Brighton Centre. Discounted dinner places are available to those attending UKDC. Award entries are now open – please visit [www.careinfo.org/dementia-awards-2016](http://www.careinfo.org/dementia-awards-2016) for further information.
The household model: care on a human scale

Mark Ivory, Editor, JDC

What is the secret ingredient, the ‘X factor’, that turns a good care home into an outstanding one? The subject was keenly debated at our annual conference with Dementia Care Matters (DCM), whose revised Butterfly household model of care was much in evidence throughout the day. Some care homes declared outstanding by the Care Quality Commission, like Vida Hall and Wisteria Lodge, were there to talk about what it took. Yet, despite these towering achievements, DCM chief executive David Sheard had some more general worries that he stated in characteristically pithy style: “The care sector is as sick as anybody with an illness, it’s a huge, sick system. The cost in delivering a malignant social psychology of care is bankrupting the care sector.”

These are strong words, of course, but it is surely true that if care homes are to thrive, when on one estimate 5,000 could go out of business in the next three years, they have to offer the people who come to live in them the quality of life they would wish for. If people think they are going to be treated as objects rather than people – the essence of malignant social psychology – they will make alternative arrangements where they can. There was a clear sense among several contributors that the ‘task and time’ culture is still with us, though all care homes now claim to offer person-centred care.

An aspect of this is to create care environments on a human scale, that is, the scale on which most of us live and work for much of our adulthood. The household model, dividing a care home with 32 residents, say, into four ‘households’ of eight people each, would seem to be one method of reinventing care homes on a human scale. No fewer than 13 of the 70 elements that make up the revised Butterfly model are about establishing these households: in short, care homes should be just that, homes and not hotels.

A further 11 elements of the model concern “being occupied”, part of which is being able to engage voluntarily in the productive work of ordinary domestic routines. We express ourselves partly through work, by doing and making, whether at home, in employment or pursuing a hobby. Crossing the threshold of care does not change this fundamental need to live life on a human scale. In Rachel Woodbridge’s article for this issue (p32), two Japanese projects enable people with dementia to do meaningful work. As one told her: “I hope to contribute to society by participating in volunteer activities. I want others to understand that people with dementia are not a burden on society. People with dementia who are not simply people who need to be taken care of.”

The X factor cannot be bottled and poured out with other ingredients to create a tasty morsel called outstanding care. It is much more elusive. But those who seek it on a human scale will be searching in the right place.
Report recommends value of gardening

The nation’s “love affair” with gardening should be harnessed by health and social care services as evidence accumulates that it can help to prevent dementia and cognitive decline. So says a report from the King’s Fund, Gardens and Health, which recommends that gardening becomes part of public health plans and that clinical commissioning groups include it as an option in social prescribing projects. In surveying the research literature on gardening and dementia care, the report says most of the quantitative studies in one review reported “a reduction in agitation due to the interventions and a trend towards reduction in verbal and physical aggression…” The qualitative studies covered in the same review found that “staff and family members enjoyed gardening and being outside, and there were testimonies of improved concentration and enjoyment on the part of their loved ones.”

Carers struggle socially and financially

Large numbers of carers are struggling to balance their various responsibilities with a detrimental effect on their health and wellbeing. A survey undertaken for Carers Week (6 – 12 June) revealed that three quarters (74%) of carers feel that their communities do not understand or value their caring role and 47% have struggled financially. Among the other findings were that 51% of carers have let a health problem go untreated and 31% only seek help only in an emergency. “Even a small amount of support can have a major impact on a carer’s life,” said Gail Scott-Spicer, chief executive of Carers Trust. “We’d like to see workplaces, the government and education services taking measures to ensure they are doing all they can to support carers in their community.”

Key factors for dementia-friendly communities

Four essential factors have been identified for developing dementia-friendly communities in a Europe-wide study by the Mental Health Foundation (MHF). They are training, education and awareness-raising; active inclusion of people living with dementia; encouraging and supporting partnerships, networks and collaborations; and securing and sharing resources. The report, Mapping dementia-friendly communities across Europe, says the 8.7 million people with dementia across the continent give rise to “both the opportunity and the necessity for creative, positive community-based initiatives” to support them. Based on a literature review, online survey and phone interviews, the report finds that most dementia friendly community activity in Europe is taking place at regional, municipal or local level with just six countries having government-led national dementia strategies. The MHF was commissioned by the European Foundations Initiative on Dementia (EFID) to do the mapping survey and create a collection of case studies, both of which can be found at www.efid.info

Museums could host music therapy

Museums could become a common venue for music therapy under a deal struck between representatives of the two sectors in a bid to improve people’s health and wellbeing. The British Association for Music Therapy (BAMT) and the National Alliance for Museums, Health & Wellbeing have joined forces to produce a how-to-guide encouraging music therapists and local museums to collaborate on services and projects that meet people’s needs more effectively. It is based on the premise that many people who could benefit from music therapy are deterred by clinical settings and that museums can be a more user-friendly way of providing services. Ben Saul, chair of BAMT Trustees, said: “This initiative helps to provide creative and dynamic ways in which care staff, it says, yet they are often more dependent than others on formal care because they are more likely to be estranged from relatives. Some fear losing their inhibitions due to dementia, while others who have come out feel unable to be open about their sexuality and transgender status.

Bob Green, chief executive of Stonewall Housing, said: “More providers and commissioners need to learn from the good practice and key recommendations identified in this report. We look forward to working with our partners to improve evidence of our communities’ experiences and to continue to drive up standards.”

The report, published with the National LGBT Partnership and entitled Dementia Care and LGBT Communities, endorses a rights-based approach and offers several case studies. It says that, while most care professionals strive to treat the people they support well, this approach “risks ignoring the very differing needs of LGBT people with dementia”. Des Kelly, who recently stepped down as NCF executive director, said: “There is an invisible population of 1.2 million likely to be affected. Highlighting best practice in this area is still difficult which is why a change of mindset is vital. Pioneering care providers are emerging to lead the way on the necessary change to improve services and we can learn from their experiences.”

Dementia strategy has overlooked LGBT people

An “invisible population” of 1.2 million older lesbian and gay people has been ignored in government strategy for tackling dementia and more care professionals are being urged to provide appropriate support. LGBT people with dementia have specific support needs which are easily overlooked by service commissioners and providers, a good practice paper from the National Care Forum (NCF) and Voluntary Organisations Disability Group suggests, and both organisations are calling for a “change of mindset.”

People worry about being forced “back into the closet” in later life by unsympathetic care staff, it says, yet they are often more dependent than others on formal care because they are more likely to be estranged from relatives. Some fear losing their inhibitions due to dementia, while others who have come out feel unable to be open about their sexuality and transgender status.

Bob Green, chief executive of Stonewall Housing, said: “More providers and

Benefits of care-based hairdressing

Dementia professionals should take more account of hairdressing as a way of enhancing people’s identities, self-expression and social participation with “scope for appearance-related support to play a far more active role” in person-centred care. That is one recommendation from the Hair and Care Project at the universities of Stirling and Manchester which concludes that there is a “compelling argument” for raising the profile of care-based hairdressing and its contribution to living well with dementia.

Horticultural happiness: Northumberland therapeutic Gardening project Blooming Well is extending its workshop programme for people with dementia thanks to a £45,000 donation from KavlTrust, the charity that owns Primula cheese. Alnwick Garden Trust, which runs Blooming Well, will be able to increase the sessions from once to five times a week with 150 attendees. Kavl UK managing director Paul Lewney is pictured (left) with representatives and members of Blooming Well. The workshops help to promote happiness and wellbeing, the project says.
Ombudsman’s report warns of ‘harrowing ordeals’ faced by older people sent home from hospital

Frail older people are being sent home from hospital alone to endure “harrowing ordeals,” the health ombudsman has said, in a report in which nearly half the patients highlighted had dementia.

Investigations related to hospital discharges carried out by the ombudsman increased by more than a third (36%) last year, which the report says indicates that people are being returned to empty homes where they are afraid and unable to cope.

Four of the nine people highlighted as examples of poor discharge practice are reported to have had dementia, including two with Parkinson’s disease and dementia who were not assessed or consulted properly before their discharge. One of them was an 80-year-old woman who lived alone and was repeatedly sent home without an assessment of her capacity to make a decision and in spite of a history of depression and attempted suicide.

In other cases relatives and carers were not told about the hospital discharge – an 85 year old woman with dementia was sent home in this way despite being unable to look after herself or get to the toilet – and patients had no home care plan in place because of poor coordination across services.

One man with vascular dementia and a personality disorder was locked in a psychiatric ward for two years because the local authority decided he was “beyond social care” and refused to fund a nursing home placement.

Parliamentary and health service ombudsman Julie Mellor said: “Our investigations have found that some of the most vulnerable patients, including frail and older people, are enduring harrowing ordeals when they leave hospital.

“Poor planning, coordination and communication between hospital staff and between health and social care services are failing patients, compromising their safety and dignity. Health and social care leaders must work harder to uncover why ten years of guidance to prevent unsafe discharge is not being followed, causing misery and distress for patients, families and carers.”

Alzheimer’s Society said its own investigations had raised concerns about hospital discharge and formed part of its Fix Dementia Care campaign. Chief executive Jeremy Hughes said: “We know from the findings of our Fix Dementia Care investigation that too many people with dementia are being discharged at night, which is unsafe, disorientating and distressing. It also increases the likelihood of them leaving without relevant information, the correct medication or the right support in place because staff are not on duty to discharge them properly.”

Care homes at risk

A quarter of care homes could go out of business within three years, according to research carried out for BBC Radio 4’s You and Yours programme. Some 5,000 homes across the UK face closure, it is claimed, because they are carrying too much debt and profits are too low to cover loan repayments. Rising costs, including the new National Living Wage of £7.20, have deepened the crisis and there is little money left over for investment in extra capacity to cover future demand. Stephen Burke, director of the Good Care Guide website, said the next 12 months were “crunch time” for care homes. He added: “Hundreds of thousands of vulnerable care home residents and their families face a very uncertain future. The government should step in.” The research found that individual care homes were borrowing about 61% of the value of their business on average, amounting to £4 billion across the industry.

Star attraction: Wigan Warriors rugby international Michael McLorum pulls a pint after opening the new pub-themed lounge in the town’s Ash Tree House care home, operated by Ideal Care Homes. McLorum tucked into some pub grub and signed autographs in what is now known as the Ash Tree Arms. He is shown with home manager Kathryn Disley.

Events and projects across the country mark Dementia Awareness Week

As hundreds of events from sponsored walks to a pier show and a cricket match at the world-famous Oval were held to mark Dementia Awareness Week (May 15 – 21), three universities in the north-west launched a new initiative to combat the disease.

They are collaborating on a range of dementia projects, including social care and strategies to live well with dementia such as music therapy and work with carers.

Research conducted by the university trio, to be called the Greater Manchester Dementia Consortium, will also encompass a project on artificial intelligence to support people in their own homes, effective support for black and ethnic minority communities, and meeting the day-to-day needs of people with young onset dementia.

The initiative by Salford, Manchester and Manchester Metropolitan Universities comes as the region synchronises its health and social care provision as part of the ‘DevoManc’ agenda, which will promote partnerships between the NHS, local authorities and academia to improve the health and wellbeing of local people.

An Alzheimer’s Society survey launched during Dementia Awareness Week found that fears arising from myths about the condition still caused more than half (56%) of people to put off seeking a diagnosis for a year or more. Almost half (49%) worried that they would be seen as “mad”.

Alzheimer’s Society chief executive Jeremy Hughes said: “We know that dementia is the most feared health condition of our time and there’s no question that it can have a profound and devastating impact on people, their family and friends – but getting a timely diagnosis will enable people with dementia to live as well as possible.”

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Housing-related services are too easily neglected, says report

Housing-related services are too often overlooked as a way of improving the mental well-being of people with dementia, claim researchers at King’s College London (KCL).

In a literature review, Living Well in Old Age, they suggest that a lack of integration between health, housing and social care has resulted in “silo working” which undermines effective management of older people’s mental well-being in the community.

Housing workers often have to deal with challenging and complex situations alone, unsupported by other agencies, while tightening eligibility criteria for services are leading to the identification of some mental health problems as a “social nuisance”, the report says. “Supporting practice and finding ways to address these challenges... seem a particularly pressing priority,” it adds.

“In this area of practice and service commissioning we do need more evidence of what works,” said report co-author Professor Jill Manthorpe, director of KCL’s Social Care Workforce Research Unit which carried out the study. “For older people the organisational boundaries between housing, social care and health services are artificial – where you live, who supports you and how, are all interconnected or should be.”

In a section on the effectiveness of housing interventions, the researchers found that there was no ‘one size fits all’ solution and that while reducing social isolation seemed to be beneficial for most older people, others valued privacy and the right to make their own decisions about their social lives. They also looked at evidence on how “smart home technology” can build capacity and independence, and how housing associations can forge links with GPs to encourage early referrals and reduce hospital admissions by training up housing practitioners.

Roughly 15% of people aged 60 and over have a mental health problem, the report says, dementia and depression being the “most common.” Forecasts suggest that the number could increase by a third over the next 15 years.

Charters of rights: One of Scotland’s leading care home charities signed two pledges to respect the rights of residents as a mark of its commitment to giving them choice and control over their support. Karen Sheridan, managing director of Community Integrated Care (CIC) in Scotland, said that adhering to ARC Scotland’s Charter for Involvement and Scottish Care’s Convention on the Rights of Residents in Care Homes would ensure that everyone received personalised care. She is shown with Scottish Care CEO Donald Macaskill (left) and CIC chief executive Neil Matthewman.

Peer groups prove their value: A social return on investment analysis indicates that peer support groups produce a social value significantly greater than the cost of the initial investment in them. To quantify the benefits of this popular intervention, researchers looked at three dementia peer support groups in south London to evaluate the outcomes and found that the social value created ranged from £1.17 to £5.18 for every pound of investment, depending on the design and structure of the group.

Key outcomes for people with dementia were mental stimulation and less loneliness and isolation while carers reported a reduction in stress and burden of care. According to the study’s authors, Elizabeth Willis, Amy Semple and Hugo de Waal, it provides encouraging evidence for those looking to commission or set up peer support groups for people with dementia and carers. The research paper was published in the journal Dementia.

News in brief

Amanda Thompsett to chair faculty at RCP
Amanda Thompsett, consultant old age psychiatrist at the South London & Maudsley NHS Trust, becomes chair of the Faculty of Old Age Psychiatry at the Royal College of Psychiatrists (RCP) on 1 July. Amanda, who takes over the RCP role from James Warner, is an editorial adviser for the Journal of Dementia Care. She said the increase in dementia diagnosis rates had helped the Faculty to highlight the importance of high quality post-diagnostic support. “Despite budgetary constraints and the added demands brought about by austerity Britain, there are many great things going on both in dementia care and more generally in the care of older people with mental health issues,” she added: “If together we can bring the best of practice out there to the many, we can produce a truly world-class service.”

Resident’s involvement with care on the rise
Although too many people with dementia lack involvement in decisions about their care, there are signs of improvement according to the Care Quality Commission (CQC). Developing activities that match the interests of residents and involving them in decisions about their care were among the top three priorities the inspectorate as one of the reasons for a marked improvement in the ratings performance of care homes. It said that 273 (73%) care homes originally rated as inadequate had improved their ratings following a re-inspection, meaning that more than 12,000 people were experiencing better and safer care. But in a new report on how people are involved in their care, the CQC highlighted historical findings to back its call for further progress. The report, Better Care in My Hands, cites evidence from a thematic review in 2014 which showed that 33% of care homes and 61% of hospitals inspected were not involving people with dementia or their families in their care or their choices about how to spend their time.

Research institute raises £250m
Funding to establish the UK’s first ever Dementia Research Institute has now reached a quarter of a billion pounds thanks to new injections of money from Alzheimer’s Research UK and Alzheimer’s Society. Each charity has added £50 million to the government’s investment of £150 million, bringing the total pot to £250 million. The institute, promised in the Prime Minister’s 2020 Challenge, will engage hundreds of researchers in the drive to understand the neuroscience of dementia and help improve care and treatment of the condition. Alzheimer’s Society chief executive Jeremy Hughes said it was the “greatest investment” ever seen in dementia research. “Critically, we have also expanded the institute’s scope to include research into care, prevention and how technology can be harnessed to tackle dementia,” he said. “We are also ensuring the voices of people affected by dementia will be influencing the research agenda going forward.” See JDC Asks, pp10-11.

Colourful mealtimes make a difference
Social mealtimes, music and a splash of colour can make the difference between malnutrition and nutritional wellbeing, claim researchers who looked at a variety of family-style interventions. The University of East Anglia (UEA) study showed that social support during mealtimes can help to avoid dehydration and malnutrition among people with dementia. It found that eating family-style meals with care-givers with music playing in the background could improve nutrition, hydration and quality of life. The research team reviewed the effectiveness of 56 interventions, including changing the colour of the plate, increasing exercise, waitress service, playing different types of music, singing, doing tai-chi, creating a home-like eating environment, providing nutrition supplements and boosting the social aspect of eating. Published in BioMed Central (BMCl) Geriatrics on 4 May.

Professor of Dementia for Salford University
Anthea Innes has been appointed the University of Salford’s first Professor of Dementia, and Coles-Medlock Director of the Salford Institute for Dementia. Professor Innes studied at the University of Stirling before moving to work at the University of Bradford with the Bradford Dementia Group, where she completed her PhD. She also worked as a Research Fellow and then Senior Lecturer at the University of Stirling, before becoming a Professor at Bournemouth University in 2011, where she launched the Bournemouth University Dementia Institute (BUDI).
Law Commission scales down changes to DoLS

Proposals by the Law Commission to replace the widely disliked deprivation of liberty safeguards (DoLS) have been radically scaled down following concerns that its initial plans were too cumbersome.

While the commission remains committed to “wholesale replacement” of DoLS, its alternative scheme of “protective care” came in for heavy criticism during a four-month consultation. Two components of this scheme have now been dropped, namely “supportive care” for people who lack capacity to decide their own living arrangements and a separate system for deprivations of liberty in hospital and palliative care settings. A third component, called “restrictive care and treatment” and intended as the direct replacement for DoLS, has been substantially modified.

The commission’s change of tack follows government criticism of the protective care scheme as too complex and expensive, and in an interim statement issued in May it admitted that many consultees felt it would be “too costly to implement.”

In the same statement the commission said: “We have therefore concluded that the new scheme should focus solely on ensuring that those deprived of their liberty have appropriate and proportionate safeguards, and should not seek to go as widely as the protective care scheme.” It added that a “more straightforward, streamlined and flexible scheme” would be recommended in the final proposals, which are expected to be published with a draft Bill in December.

It seems likely that the proposed role of Approved Mental Capacity Professional, replacing Best Interests Assessors, will be rein in and focused on those whose rights are most infringed, particularly in relation to the right to a private and family life.

The restrictive care and treatment scheme is intended to streamline the assessment process and shift responsibility for establishing the case for a deprivation of liberty on to NHS and local authority commissioners and away from care providers. Justifying its decision to drop the bespoke scheme for hospitals, the commission said its revised proposals were “sufficiently clear and straightforward to apply in any setting”.

Dementia Diaries

People living with dementia from five DEEP groups across the UK have been trained by On Our Radar to use simple 3D printed mobile phones to record audio diaries, capturing their own thoughts and experiences of living with dementia as they occur. In this column, the Dementia Diarists share some of their audio diaries, a process which they hope will prompt dialogue and promote understanding.

This month, our columnists share some of their experiences of travelling with dementia and how they continue to remain active in new environments.

Keith Oliver, 60, explains how, since receiving his diagnosis, travel is still manageable and enjoyable, but only if you plan well and put practical measures in place.

“Travel to me is such a crucial part of living well. The day I was first diagnosed we’d got a holiday booked to Australia. We were really looking forward to it, everything was planned, everything was paid for. The GP said, don’t go. Most people would suggest we do what the consultant said, but me being a bolshy so and so I thought, well, no, I am not going to listen. You know, I want to… this holiday is important to us. We did modify the itinerary. We did contact the friends we were going to stay with and tell them what it was I was now dealing with, and they were very happy to be hospitable with us and to spend time with us of course. And it made no difference whatsoever. I think there’s a lesson to be learned there. I suppose the key elements are dealing with travel agents, dealing with your medical team who are supporting you, and dealing with insurance, and the actual itinerary of your holiday. You simply have to put in place sensible measures to allow you and people with you to be safe, comfortable, happy and secure. And all the time you are considering that, and you are modifying it as the needs change. But ultimately the biggest need is to go and enjoy yourself, and to be safe.”

Dianne Campbell, 49, describes her upcoming solo trip abroad and her concerns about travelling alone with dementia.

“I’m a bit worried about travelling on my own and also about insurance. People say “oh, you’ll be fine”, but I haven’t travelled alone since my diagnosis. I’m planning a round trip. I’m planning to get into Canada and then into Jamaica in September or October. This trip that I’m planning by myself, and so I’m wondering for other people, how do they cope? I need some ways of how do I cope with travelling by myself with my dementia. And I’m so looking forward to hearing back some good feedback, you know, things I can put in place of how to do my travelling confident and relaxed.”

Anne Scott, 48, shares her experience of her first holiday since being diagnosed with dementia and MS.

“I was very fortunate in being invited to an MS awards ceremony in London with my daughter, but I was extremely worried about the travel arrangements, and if I could still manage to enjoy myself. I have never been to London so I was very excited and determined to manage it. My daughter and I used the internet to work out the closest airport and hotel then booked it online. We also managed to book a taxi to take us from the airport. This cut down on travel time for me and lessened my apprehension a little. Once at the hotel I explained my difficulty to reception about arranging further travel. Then they offered to book me taxis to wherever I needed to go and informed me when it had arrived. They also gave me leaflets for local tourist attractions and helped me with travel times and costs to get there. This made my stay much more relaxing and, I think all hotels should offer this service or have dementia friendly leaflets available on reception. So, try and arrange all the details before leaving, research or ask advice from fellow travellers, think about things like your walking stick or other aids, dress comfortably, and lastly do not be shy about letting others know you need that extra little bit of help. Doing so made my holiday less stressful and tiring and therefore enabled me to save my energy for the MS awards ceremony which was a truly fantastic and memorable day.”

Find out more and listen to the Dementia Diaries at dementiadiaries.org. DEEP is a growing user movement of influencing groups of people with dementia across the UK. For more information visit www.dementiadiaries.org.uk

Piece of cake: Care home chefs in the south of England baked cupcakes for their residents to mark Alzheimer’s Society’s Cupcake Day in June. At Avon Reach, run by Colten Care in Mudeford, Dorset, the chef trialled a range of yellow and orange designs based on the colours and shape of the company’s ‘double-C’ logo. Residents Dorothy Green (left) and Doreen Friddle are pictured with chef Izabela Turczyn.
The Dementia Research Institute has much to prove in relation to psychosocial research on dementia. First indications were hardly encouraging. The impression was given that it was only a late intervention by Alzheimer’s Society, which contributed significant additional funding, that managed to get ‘care, prevention and technology’ on the agenda at all.

Some might argue for a separate institute, fearing that research on care and prevention will inevitably be engulfed by the drive to find ‘the cure’. I would argue that pharmacological research needs better psychological understanding of the indicators of the dementias and of how people make sense of their experiences.

The dementias are complex conditions, and an Institute on the scale envisaged should have multiple priorities. Prevention, through modification of known and emerging risk factors is an area that has been under-researched, and will need coordinated efforts to develop studies that are large enough and of sufficient duration to produce robust results.

However successful the research on finding a cure turns out to be, it will be many years before the benefits for those developing the condition are seen. In that time millions of people will experience the impact of dementia and it is imperative that we do all we can to improve their quality of life, and assist them to live as well as possible. As the Dementia Research Institute will recognise this and act accordingly.

Professor Bob Woods is director of the Dementia Services Development Centre, Bangor University.

There are 670,000 people in the UK acting as primary, unpaid carers for people with dementia saving the government an estimated £11.6 billion each year according to Alzheimer’s Society.

The Prime Minister’s 2020 Challenge highlights the fact that people with dementia want to live at home for as long as possible and continue to be an important part of their community and civil society. If this vision is to be realised then carers need to be better recognised and supported as they are vital in the realisation of this vision.

Carers are of course interested in research that may one day lead to a cure; however, vastly more important to them is how to help the people they care for now. Better research into managing changes in behaviour and dealing with incontinence is what carers would celebrate because they are pivotal when it comes to a decision whether they can continue caring at home or whether they should consider the possibility of residential care.

It is widely recognised that carers of people with dementia go on to have poor health outcomes themselves. As dementia progresses carers find they are physically exhausted and exposed to limited or no stimulating conversation. It would be wonderful to see some research around reducing the negative impact on carers’ physical and mental health.

It is vital when considering opportunities for research that dementia is a diagnosis for the whole family not just one person.

Louise Marks is dementia and older carers policy and development officer at the Carers Trust.

Initial plans for the Dementia Research Institute focused on biomedical research into causes and medical treatments, but in a recent announcement Alzheimer’s Society undertook to contribute £50m to ensure the inclusion of research on care, services and public health. This has opened up new possibilities for researchers like me who are interested in how we can best enable and support people with dementia and carers.

I would like to see a strong focus on examining what influences the potential for living as well as possible with the condition and identifying what individuals, communities, service providers and policy makers can do to ensure that people with dementia and carers are supported and have the resources they need to be able to live well.

As part of this, I would like to see intervention research, based on a philosophy of enablement, which aims to find ways of supporting people with dementia to function at the best possible level and remain as independent as possible. This would involve applying the principles of rehabilitation or reablement to support autonomy, reduce excess disability, and encourage participation in meaningful activity and social relationships.

For people with more severe dementia, a similar approach could be applied to enable the expression of wishes and preferences and ensure responsive care. As well as identifying effective approaches to working with individuals, research should be directed at understanding how we can develop and transform services to ensure that these principles permeate every contact with people with dementia and family carers.

Linda Clare is professor of clinical psychology of ageing and dementia at the University of Exeter.

It’s amazing to think of this amount of money being invested in dementia research. It would have been unthinkable a few years ago. However, let’s just note that the £250 million for the Dementia Research Institute covers a 10-year period from 2020; in contrast Cancer Research UK spent over £450 million in 2013-14 alone. There is some way to go yet to achieve parity.

My personal view is that a ‘cure’ for dementia is unrealistic. What we are more likely to achieve is a set of treatments that may be appropriate for people with different variants of it. By chipping away at individually tailored therapies, much in the way that happens with some cancers, we may make some progress.

In the meantime, over three-quarters of a million people are living with dementia now, alongside similar or even larger numbers of family carers, so we need to be thinking about how we help people here and now, not just in the future.

Individual cohort studies, like the MRC Cognitive Function and Ageing Study (CFAS), are vital but so too is bringing them together with initiatives like the UK Dementia Platform that can also help bring individuals closer to participating in research into new treatments. We need to do more research about prevention too.

Finally, I welcome how people living with dementia and the public have become more active and engaged in all aspects of dementia research and would want to see this continue to develop.

Tom Dening is professor of dementia research at the Institute of Mental Health, University of Nottingham.

Funding for the Dementia Research Institute promised in the PM’s 2020 challenge has reached £250 million with the aim of increasing understanding and improving care and treatment of dementia. What should its top priorities be?
The huge commitment of £150m of government funding for the Dementia Research Institute is something JD C readers could hardly have dreamt about in the early 1990s when the journal started. But with money comes attention, sometimes envy and often great expectations. So, to take the title of one of my favourite books, Roald Dahl’s BFG, how can the DRI be a Big Friendly Giant?

‘Big’ does not mean just having a big bank balance – it means managing this investment well, ensuring governance is proportionate, and that there is accountability. While multiple funding streams are welcome, they can lead to complex accounting and accountability processes.

‘Friendly’ is a good term to think about when devising the values or ‘mission’ statement accompanying the business plan. Even if we can’t all agree on what ‘friendly’ looks like – we probably all know which organisations feel unfriendly. Communication with the whole of the dementia workforce (not just health but also care and housing) will need to be visible. The BFG was friendly of course, but other giants not so.

And lastly being ‘Giant’ can be uncomfortable – those working at ‘office’, lab or research unit roles might do well to follow the Department of Health’s civil service example of being expected to spend days on the frontline of services. I have heard several civil servants – of all grades – speak positively of the impact this makes.

So welcome BFG – sorry, I mean DRI.

Professor Jill Manthorpe is director of the Social Care Workforce Research Unit at King’s College London

Hopefully the Dementia Research Institute will be asking the question at the top of this column of people living with dementia. This key group should have a central role in shaping the direction and priorities of research in the field.

One area that seems neglected relates to diversity of people experiencing dementia. As diagnosis rates rise, dementia awareness increases in the public domain, as do representations of those living with a diagnosis. These portrayals in television drama and films typically feature a white man or woman living in a traditional heterosexual nuclear family situation. This is reproduced in public awareness campaigns and news coverage about the condition.

Dementia does not discriminate according to (for example) ethnicity, sexuality, living situation or social class, yet these dominant representations combine to suggest otherwise. This erasure of experience has been largely perpetuated by dementia research with a tendency for dementia to be treated as a category within which gender, ethnicity, class, sexuality and so on are not relevant, although an expanding body of work tells us that people experience things like access to services differently depending on some of these markers.

What about single people? People who have never had children? People living in extended family situations? People who identify as lesbian, gay, bisexual, transgender or queer? What might the psychic impact be for someone who never sees anyone ‘like them’ represented in information about dementia or representations of it? Dementia research cannot fully speak to the needs of people living with a diagnosis without considering some of these questions.

Dr Katherine Ludwin is research associate, Journeying Through Dementia, University of Bradford
Dementia among Gypsies and Travellers

In the first of two articles looking at the impact of dementia on Gypsies and Travellers, Mary Tilki and colleagues explore the challenge for services

Although Gypsies and Travellers have a very low life expectancy, there is growing evidence of dementia in these communities. They experience extremely poor health, and much of this has the potential to increase the risk of dementia. Factors related to the lifestyle and experience of travelling people increase the risk and make it more difficult for people with memory loss and their families to cope with the condition.

There is a growing body of research around the health of Traveller communities (for brevity we’ll use this term to include Gypsies), but very little relating to dementia despite increases in prevalence reported by community organisations (LeedsGATE 2015, MECOPP 2012). Here, we will explore some of the challenges for services and a few of the beliefs and experiences to be taken into account when reaching out to travelling communities.

There are three main ethnically defined groups which come under the term ‘Gypsies and Travellers’: Romany Gypsies, Irish Travellers and Scottish Gypsy Travellers. Romany Gypsies are a related group whose ancestors are believed to have left India in a gradual diaspora across the world from 1000 AD and are first recorded in the UK in the 1500s. Irish Travellers are distinct from other Irish populations and it is argued that they have been a specific group for about 3000 years (Gmelch & Gmelch 2014). Scottish Gypsy Travellers may have ethnic links to both Irish Travellers and Romany Gypsies, but have recently been recognised as distinct from both groups.

The inclusion of a Gypsy or Irish Traveller category in the 2011 census generated a self-defined population of 58,000 people in the UK (ONS 2014). However civil society groups argue this is a significant undercount, reflecting authorities’ inertia in obtaining the data (LeedsGATE 2015, Prior 2013). There are clear difficulties getting information about Travellers, but at the same time little effort has been made to obtain the data needed to plan services (Prior 2013, Inclusion Health 2013, KMPHO 2014). Aggregating several groups into a single category masks differences in culture and ignores socio-economic, health and illness profiles which differentiate them.

Poor health status

Research over the last decade demonstrates that the health of Travellers is worse than that of the general population in socially deprived areas (Parry et al 2007, Ryan et al 2014). Travellers have high levels of cardiovascular disease and an increased risk of diabetes (European Union 2014, Greenfields 2009). Chronic physical and mental illness exacerbates social isolation in an already excluded society and all increase the risk of dementia in a community with low life expectancy.

Despite this health profile, Travellers find access to health services difficult (van Cleemput 2012). The travelling lifestyle or being unable to register with a GP leads many Travellers to go straight to A&E (KMPHO 2014). Literacy is a barrier, precluding those who can’t read information or use online resources. Discrimination breeds mistrust of officialdom and previous insensitive encounters with health professionals make people reluctant to seek help. However when a GP, health visitor or community nurse is trusted, Travellers will return from travelling to consult them (Cemlyn et al 2009, KMPHO 2014). These barriers are exacerbated for people who develop dementia and impact disproportionately on those who care for them.

While there is a growing body of research on the health of Travellers in the UK and more widely (Greenfields 2009, Goward et al 2006, Dion 2008, KMPHO 2014, RCPG 2013), there is as yet limited consideration of dementia (Truswell 2013). It is unclear whether the low levels of recorded dementia relate to short life expectancy, lack of access to GPs or low diagnostic rates in general. Community organisations suggest that lack of awareness of dementia and perceptions of memory loss as a normal part of ageing are factors, but worrying they are seeing people with dementia at an earlier age than would be expected (LeedsGATE 2015).

Coping and caring

The difficulties of caring for a relative with dementia are magnified for Travellers for practical, psychological and cultural reasons. Nonetheless, Traveller families expect to care and do so willingly, not seeing themselves as carers (APPG 2013, MECOPP 2012) but as families doing what families do. Invariably the bulk of caring relies on women, but even when relatives rally round, one person often undertakes most of the caring. Carers often misunderstand dementia, assume forgetfulness or confusion are features of ageing but are embarrassed to talk about this outside the family (APPG 2013, Truswell 2013). Norms of respect additionally generate reluctance to talk about this to an (older) person or to take action which they think their loved one might dislike.

The shortage of sufficient, decent Traveller sites (KMPHO 2014) adds to the stress of people living with or caring for somebody with dementia. Inadequate facilities make helping with hygiene, toilet use or additional laundry more difficult. Travellers with dementia used to being on the move risk wandering off the site and getting lost. Keeping a confused person safe on a site where cars are broken or metal recycled poses an added difficulty.

Travellers with increasing disability can feel forced to move into housing and those obliged to support a relative with dementia on a site or in housing experience isolation from family, community and
traditional ways. Men used to an outdoor life feel especially caged in, missing contact with animals, green spaces and freedom to roam. As recent memory rolls back, people with dementia may become agitated recalling memories of forced eviction, hostility and even imprisonment.

**Health beliefs**

There is a culture of self-reliance among Travellers, coping with problems within the family or community. Being in control is important and Travellers are reluctant to be a burden. They are more likely to provide 50-plus hours of informal care to family members each week than the general population (ONS 2014). They are clear about their duty to sick or elderly family or community members each week than the general population (ONS 2014). They are clear about their duty to sick or elderly relatives and the idea of a care home is deplorable to them (van Cleemput et al 2007a).

Reluctance to seek external help can arise out of respect for the person with dementia or the inappropriateness or cultural insensitivity of services. It can also be due to pressure from the family or community and women often feel unable to express distress or burnout because of cultural norms and respect for the person they are caring for. They may see this as ‘giving in’ or being weak (MECOPP 2012) or they may fear reproof from the community if external services are sought. However, this does not mean that families will not accept help if it is negotiated by a trusted professional and allows them to care in a manner meaningful for them and which respects Traveller ways (MECOPP 2012).

Travellers widely believe that illness in general is caused by stress, environment, accommodation and any threat to the travelling lifestyle (Cemlyn et al 2009.) They often show fatalism about illness and little confidence in doctors’ ability to treat it, coupled with low expectations of their health and a tolerance of chronic conditions (RCGP 2013, KMPHO 2014). Dementia itself is often seen as an inevitable feature of ageing about which nothing can be done (KMPHO 2014).

Travellers may seek help only in a crisis because of their beliefs, fears and mistrust of health professionals.

**Addressing barriers**

The greatest barrier to timely access to diagnostic or support services is Travellers’ past experiences of trying to obtain social care. MECOPP (2012) highlighted how approaches to social services often resulted in inappropriate or unhelpful responses, cases closed or left without a care package in place. Being listened to can be a rare experience for Travellers and somebody who is struggling may not have the physical or emotional energy to battle with services who at best don’t understand or at worst don’t care. Muddling through alone or with the help of family may be more dignified and expedient.

What is clear is that further research is necessary, especially for data to challenge assumptions that lower lifespan means lower levels of dementia. Commissioning bodies should reach out to Travellers, through respected professionals or community groups, to identify what is needed and what culturally appropriate services mean to them. They should offer help proactively rather than assume it will be rejected, and there is potential to train Travellers as lay trainers and advocates in relation to dementia and healthy lifestyles, which might ultimately reduce the risk.

After all there is a legal obligation to address health inequalities faced by people with dementia and Gypsy Travellers. In our next article we will look in more detail at what commissioners can do.

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Campaign for carers to stay in hospital

John’s Campaign argues that carers should have the right to stay overnight in hospital if their loved ones have dementia. **Phil Harper** explains how it was implemented in Hampshire.

It is undeniable that hospitals can be scary places for someone with dementia, but it is equally the case that hospitals could do much more to make it easier both for the patient and their family. One answer is to enable carers to spend more time with their relatives in hospital, giving the right to stay if their loved ones have dementia. Started by *Observer* journalist Nicci Gerrard, whose father John had Alzheimer’s disease, John’s Campaign (2016) argues that carers can be a vital source of comfort and stimulation.

Patients with dementia account for 3.2 million bed days a year in hospitals and up to half of the patients admitted may have the condition (Boaden 2016). So this is core business in acute care and we should ensure that we address the needs of this group of people. Alzheimer’s Society’s Fix Dementia Care campaign report demonstrates that vast improvements in hospital dementia care are necessary, including carer involvement and support.

A review of the literature shows there is a distinct lack of communication between hospitals and carers of people with dementia (Andrews 2015, Boaden 2016, Douglas-Dunbar & Gardiner 2007, Jurgens et al. 2012). Allowing a carer to pass on expert knowledge of the person they care for can help educate staff and deepen their understanding.

There is a dearth of qualified nurses and some hospitals are experiencing staff shortages (Ford 2013) meaning that aspects of care for people with
dementia can be missed, in particular psychological needs and assistance with mealtimes (Andrews 2015). Carers can provide essential social interaction, where nurses simply do not have time, and often enjoy helping out with meals (Andrews 2015). Carers who visit often and assist with many aspects of care, as they do at home, help bring a sense of normality and enforce the set routine that is important for a person with dementia (Andrews 2015). Their involvement also helps to meet their own need to carry on caring for their loved one, especially where older carers are concerned (Coleman & O’Hanlon 2004).

**Strengthening carer involvement**

Hampshire Hospitals NHS Foundation Trust successfully implemented the aims of John’s Campaign across all wards in its three hospitals during Dementia Awareness Week in May last year. This gave carers open visiting hours and encouraged them to participate in aspects of the care of the person with dementia.

The Trust’s dementia specialist team visited all wards to discuss the campaign with staff, raise awareness and answer questions, as well as messaging everyone by email. Ward staff raised all manner of concerns, such as “where will people stay if they want to stay the night?”, “what about privacy?” and “will there be space for all the relatives?”

Once we were able to talk them through, these concerns diminished because ward staff realised there were easy solutions like allowing people to sleep in the chair next to the patient’s bed with pillows and blankets provided by the hospital.

It is interesting to note that there have not been many carers staying the night, but those who have have been more than happy with this solution. In respect of privacy there might be times when the carer has to leave the bed area, but this does not happen often. As the dementia team pointed out, other patients in the bay are members of the public too and then it is just a simple matter of pulling the curtain across when the privacy of a particular patient has to be protected. The same should apply to carers, who we find understand the need to leave the bay temporarily to allow nurses to get on with their work. They also appreciate that it is not possible for large numbers of people to sit with a patient outside of regular visiting hours and normally only one or two family members at a time take advantage of our new flexible arrangements.

**Positive feedback**

Feedback from carers and staff alike has been very positive about John’s Campaign and its implementation at Hampshire Hospitals. Families have found that it is reassuring and makes visits to loved ones more practical, especially if they do not live close by. Numbers participating have been approximately two or three carers on a ward at any one time. Many will stay for the first couple of days but when trust has been established with the hospital they often feel comfortable taking time out. Although they help meet the patients’ needs for assistance with eating meals and social interaction, there are other needs like personal hygiene that they do not meet, allowing them to take back the everyday role of being a family visitor.

Staff have also benefited from the implementation of John’s Campaign. The contribution of carers at mealtimes is enormously helpful, especially during shifts with limited staffing, and patients appear to achieve better outcomes particularly in terms of physiotherapy and getting mobile again. Carers, through working in partnership with staff, also say that they learn new techniques on how to care for their loved one, for example, learning how to assist and promote independence when a person is mobilising on the ward. These new techniques are useful to both carer and patient on discharge, ensuring continuity of care and reducing the likelihood of further admissions.

There are many benefits of involving carers in the care of a person with dementia, not just, to the carer and patient but also to the hospital and staff on the wards. More needs to be done to strengthen the partnership, but with the help of John’s Campaign hospitals are moving in the right direction.

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Phil Harper is an associate practitioner in dementia care for the dementia specialist team at Hampshire Hospitals NHS Foundation Trust.
Communication skills: emPoWereD Conversations

Ordinary communication between people can be disrupted by dementia, but a new training programme offers a solution. Sue Bellass (left), Phil McEvoy and Tracey Williamson report.

Communication is a core aspect of human experience and has a profound effect on the quality of our lives. Being able to express ourselves, and to understand other people, shapes our sense of who we are and how we connect with our social world. The experience of dementia can disrupt interactions between people, potentially leading to frustration, misunderstandings and alienation (Snyder 2006). Here, we will report on a communication training programme designed to overcome some of these difficulties.

In the earlier stages of dementia the difficulties may be relatively minor such as problems finding words and maintaining the thread of a conversation. As the condition progresses, it can become increasingly difficult for people with dementia to pick up on social cues, make themselves understood, and deal with changes in their perceptual reality. Family and professional carers, and the people with dementia they care for, may struggle to deal with difficulties in their relationships caused by these communication impairments.

Research has demonstrated that communication skills training for family and professional carers can increase their use of positive strategies and can improve the quality of life of the people they care for (Eggenberger et al 2013). However, there is relatively little provision available and existing training programmes often focus on the pragmatic elements of communication, such as eye contact, tone of voice and pacing of speech, paying scant attention to the emotional and relational impact of communicative difficulties.

EmPoWereD Conversations

‘EmPoWereD Conversations’ is a new and innovative approach to communication skills training developed by Six Degrees Social Enterprise and the University of Salford. It is designed to help family carers and professionals listen, learn and connect with people they care for who are living with dementia by focussing on their practical and emotional needs. The EmPoWereD Conversations approach aims to enhance carers’ and professionals’ abilities to understand the emotional processes occurring during communication, thereby helping to cultivate relationships based on equality and common understanding rather than power and dependency.

A course comprises six one hour modules delivered by a trainer. Using a series of interactive and reflective exercises, course attendees:

• consider what it is like to talk to someone with dementia and what it might feel like for a person with dementia to communicate
• explore the barriers that inhibit conversational interaction with people with dementia
• learn strategies to assist in dealing with the conversational barriers faced by people living with dementia
• examine how we communicate ‘without talking’ and the ways in which barriers to communication are connected to our emotional responses
• reflect on situational encounters where the strategies explored are used in practice
• review lessons learnt and celebrate stories of success.

The modular structure of the programme enables attendees to put learning into practice between sessions, thereby reflecting on their real-life experiences throughout the course. Learning interactively from one another, in a supportive, facilitated group session, has proven to be a key aspect of the effectiveness of the course.

Exploring barriers to communication helps attendees both to develop a deeper awareness of their own behaviour and to consider the perspective of the person with dementia. Innovative methods are used; in one such exercise attendees are given an A4 piece of paper and asked to draw a pictorial representation of a real-life experience of communicating with a person with dementia. Drawing can often help bring to the surface unspoken thoughts and emotions. In one particular instance a family carer, Jenny, developed new insights after drawing a picture of herself ironing at her mother’s house. Her mother has dementia and feels unable to assist with household tasks, a perception that causes her frustration and distress, as Jenny notes:

‘She often says, ‘I don’t do any work any more, I don’t do any work any more’ and ‘you’re having to do everything for me, that’s awful isn’t it?’

In the image, Jenny depicts herself doing the ironing with her back to her mother. In creating the picture, Jenny became aware that she was subconsciously creating a physical barrier to...
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9.00 - 9.40  Registration
            Refreshments and exhibition viewing

PLENARY SESSION
9.45 - 9.50  Welcome
            Tessa Gutteridge, YoungDementia UK & Hilda Hayo, Dementia UK

9.50 - 10.10 Keynote Address
Professor Alastair Burns, National Clinical Director for Dementia

10.10 - 10.55
What we needed on diagnosis - solutions based on personal experience. Keith Oliver, Kent & Medway NHS & Social Care Partnership Trust

Essential elements in a care pathway for every person with young onset dementia. Janet Carter, North East London Foundation Trust & University College London

Questions and discussion

10.55 - 11.10
Meeting the needs of younger people with dementia – where are we now and where are we going? A national overview from the Alzheimer’s Society. Adrian Bradley, Alzheimer’s Society

11.00 - 1.00 Lunch and exhibition viewing

2.00 - 3.20 PARALLEL SESSIONS
Choose one from A and B below:

A. Life after diagnosis: working creatively
    Adjusting to life after diagnosis of frontotemporal dementia.
    Chris Norris, Dementia Service User Envoy
    Working creatively with existing services to serve the needs of people with frontotemporal dementia and other rare dementias.
    Jeremy Smith, Birmingham & Solihull Mental Health NHS Foundation Trust
    On the work of the National Young Onset Dementia Network.
    Sarah Plummer, YoungDementia UK

B. Employment and work opportunities
    Keeping me employed - what works and what doesn’t.
    Wendy Mitchell, person living positively with dementia

3.25 DEEP/YDUK Workshop feedback
    Rachael Litherland, Innovations in Dementia and workshop members.
    Plus: To forget with grace – poems about the everydayness of living with dementia.
    Jacqui Peedell, living with young onset dementia

3.50  Close
communication, and that encouraging her mother to help with the task might open a channel for conversation and alleviate her feelings of distress at her perceived inability to help:

The ironing thing is something that I do very regularly and it suddenly occurred to me that that very regular thing probably wasn’t as meaningful as it could be… It’s a simple physical activity but my mum doesn’t really join in any activities in the house any more and she can very easily just pass me a garment, and then maybe she might not feel quite so much like that.

In a post-course interview, Jenny reported that she had repositioned herself when ironing so that she faced her mother, and that she now played one of her mother’s CDs during the task. She observed that another important issue she had learnt from the course was to focus on the present rather than the past when talking to her mother, and playing the CD gave them the opportunity to talk about the music as they listened to it:

We bought her a CD for Christmas, so I said, ‘would you like to listen to that while I do the ironing?’ She said, ‘oh yes, that’s a good idea’ so we had that on. I took on board some of the things that we talked about on the course about conversations being good if they’re very much about the here and now so we were able to say, ‘oh did you like that song, that was nice, wasn’t it? Ooh hasn’t she got a good voice?’ so we could talk literally about exactly what had happened earlier in the day.

Creating the picture, then, helped Jenny to gain new insights into her actions and to consider alternative ways of dealing with the situation to improve communication. Involving her mother as an active participant in the ironing rather than as a passive recipient of her help did something to redress the power imbalance that existed in their relationship and alleviated her mother’s distress. Focussing on what was happening in the present and concentrating on engaging in meaningful, reciprocal interaction.

Training outcomes
Attendees have reported that the course improved their knowledge of the complexity of communication, the barriers that might exist, their emotional experiences during interactions and the importance of being present in the moment with people with dementia. Attendees have also said they have been able to:

• consciously reflect on communication with a person with dementia, considering their own emotions and how the person with dementia might feel.
• be relaxed, not have an agenda and to allow the conversation to change track.
• invite conversation via statements (offering an invitation to respond) rather than asking direct questions, which may make the person with dementia feel inadequate if they struggle to answer.
• be continually mindful of possible barriers to communication, including body language and the physical environment as well as verbal difficulties.

Professional carers, such as day care staff and staff in nursing homes, have reported similar experiences. One nursing assistant captures the improvement in her approach and the difference it made to Mary, a fiercely independent resident in the care home she works at:

I’ve tried to avoid using any language that feels that I’m correcting or disputing. If they feel that you’re someone else or they feel that they are in a different place than where you are, just go with it and keep the conversation flowing.

Mary had been angrily resisting the efforts that were made to help cut her nails and comb her hair. After attending an emPoWereD Conversations course, the nursing assistant adopted a new approach to engaging with Mary. Instead of trying to deal with the issue of her and nails directly, she concentrated on engaging Mary in conversation and actively listening to her. Mary appeared more at ease and became happy to co-operate with the chiropodist and hairdresser, which was a major breakthrough.

Conclusion
Communication skills training that explores the emotional aspects of interpersonal communication in addition to the pragmatics such as tone, eye contact and pacing of speech, can benefit both family carers and professionals. For staff, it can enhance their ability to provide person-centred care and can give evidence of reflective practice for professional revalidation. For family carers, training offers an opportunity to improve their relationships with their relatives by reducing the distress and frustration that can be caused by misunderstandings.

References
Sue Bellass is doctoral researcher at the University of Salford, Dr Phil McEvoy is managing director of the Six Degrees Social Enterprise and Dr Tracey Williamson is reader at the University of Salford. For further information contact phil.mcevoy@nhs.net
“Christie & Co have been delighted to be involved in the National Care Awards since its inception. It remains one of the sector’s premier events, attended by the whole industry, whilst retaining its ethos of highlighting the work done by individuals on a day-to-day basis, providing quality care. It is crucial to showcase all that is good in the sector and remind everyone of the commitment and sheer hard work by many people across the UK.”

- Richard Lunn, Director & Head of Care, Christie & Co

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Partnership working to improve diagnosis and care

Derek Dodd, Carlvin Josephs and Diane Bardsley describe how Dorset more than doubled diagnosis rates when they were the lowest in England, and improved support for people with dementia and carers before and after diagnosis

Six years ago diagnosis rates for dementia in Dorset Primary Care Trust were the lowest in England at 26%. As a result, many people had no diagnosis, no access to treatment, and were denied the opportunity to plan for the future while still able to do so.

Following publication of the National Dementia Strategy in 2009, we wanted to change things for the better. Our aim was to ensure that significant improvements were made in the key areas identified in the strategy, including:

- more dementia awareness in the community and across health and social care services
- higher quality care to enable people to live well with dementia
- improved awareness through effective advice and support around dementia.
- removing the stigma surrounding dementia.
- consistently improving the delivery of education and training for professionals at all levels and in all settings.
- developing and commissioning a range of services for people with dementia and their carers which fully met their changing needs over time, within an agreed funding package.

Following an evaluation by Bournemouth University Dementia Institute, the Memory Gateway service was set up with the additional aim of providing a more integrated pathway of support, screening, assessment and treatment. This would improve access to services and reduce duplication, making the system less confusing and increasing the rates of dementia diagnosis. Memory Gateway aims to encourage people to access memory services who may be reluctant to visit traditional mental health secondary care services, screens carers for depression and anxiety, and provides people diagnosed with dementia and carers with appropriate support, advice and information.

The service, commissioned by NHS Dorset Clinical Commissioning Group (CCG) and the local authorities for Bournemouth, Poole and Dorset, was launched in September 2014. Providing the service were Alzheimer’s Society and the Memory Assessment Service at Dorset Healthcare University Foundation NHS Trust. Pilots were previously undertaken in various GP practices, including a six month trial in Bridport Medical Practice. This tested new working arrangements for detection, diagnosis and support for people diagnosed with dementia or mild cognitive impairment (MCI) and feedback from it led to modifications resulting in the current service. Since its launch Memory Gateway has received over 4,500 referrals and people using the service now have one point of access. Referrals can be made by phone, letter or secure email, by anyone including self-referral, primary care, community mental health, intermediate care, and reablement teams. Other health and social care professionals working in either acute or community settings can also refer.

The service works across all 13 Dorset CCG localities and is determined by the needs identified in each locality. By sharing their knowledge and expertise, the CCG and the

Case study examples

These brief case studies are based on the experiences of Memory Gateway memory advisers:

- Mrs S was very pleased that her husband was willing to try the day centre and feels that if it is successful it would give her time to herself. Also just knowing that she had our number to call if she required any further support or information was reassuring (following a client referral by the memory adviser to a day centre).

- During the visit, I was able to give him some information about the dates of the local Memory Café. He said he knew the venue well as he still goes to church there and was going to give it a try the next day. Since then, he reported that he had enjoyed it and would be going back to next one.

- Following the visit, I contacted the local district council who were going to send him a registered council tax exemption form which he would be able to take to his GP to complete and sign. I also printed out and hand-delivered the attendance allowance forms with a stamped addressed envelope to the gentleman and arranged for an Age UK volunteer to help him fill in the forms. When I spoke to the volunteer later that day, he said they had successfully filled in the forms together and posted them off.

- During a post-diagnosis visit to support the carer (whose wife has dementia) he and his daughter expressed a need for some advice on how to cope with certain behaviours which they found difficult. I spoke with my line manager and we did a second visit together. She has some expertise in this area and was able to give the family some invaluable advice and guidance. The carer now reports that they are coping much better and really appreciate the help given.
providers have been able to improve service delivery, discussing and resolving any problems quickly. By February this year the diagnosis rate for Dorset CCG had reached 62.4% – well over twice the rate in 2010 – with 1,356 patients diagnosed by the Memory Assessment Service during April – December 2015 alone.

The partnership approach to service delivery has been helpful in other ways, not least in that the health and social care needs of people with dementia and their carers can be addressed simultaneously through one point of contact. Carers can be signposted to appropriate services or information.

GPs in most localities have been introduced to Memory Gateway through education sessions at three major acute hospitals and a number of community hospitals. An example of the interest in the service among GPs is that, following a well attended and much approved talk on dementia given by a Memory Gateway memory adviser at one GP Surgery, the lead GP there offered the facility for the Memory Support and Advisory Service to have a monthly presence at the surgery.

Now plans are afoot to expand post-diagnostic services, given the increase in referrals from rising numbers of people recently diagnosed seeking information and support. A review of specialist dementia services is already under way, led by Dorset CCG, recognising the need to enhance these services following the success of Memory Gateway.

Derek Dodd is operations manager at Alzheimer’s Society in Dorset and Somerset; Carlvin Josephs is community mental health service manager at Dorset Healthcare University NHS Foundation Trust; and Diane Bardsley is principal programme lead, mental health and learning disabilities, at NHS Dorset Clinical Commissioning Group.

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Using sensory stories with individuals with dementia

People with dementia are prone to sensory deprivation, but symptoms like irritability and confusion can be avoided by using multisensory life stories. Rebecca Leighton, Coralie Oddy and Joanna Grace describe two successful approaches to sensory life story work with individuals with profound and multiple learning disabilities (PMLD), became popular in dementia care in the 1990s (Baker et al 2003, Hope & Waterman 2004).

Individuals with PMLD and dementia are certainly not a homogeneous group, but this overlap in approaches reflects the fact that both populations are vulnerable to sensory deprivation (Baker et al 2003, Bauer et al 2015, Fowler 2007, Grace 2014) and have an increased need for non-verbal communication (Ellis & Astell 2008, Mansell 2010, Mencap 2014). The parallels suggest that ‘what works’ in sensory storytelling for people with PMLD could be beneficial in dementia. Through exploring this in practice, we have developed two approaches: personalised sensory life stories and group sensory storytelling.

Sensory life stories

Traditional life stories are usually books (Kindell et al 2014, McKeown et al 2006) but other formats exist. They may incorporate photos, documents, objects or music (Hewitt 2006) and are thus experienced via multiple senses. However, they may “... lack a multisensory and embodied dimension that requires further exploration in research and practice” (Kindell et al 2014, p158). So, since 2013, we have had a multisensory focus, implementing sensory life stories with individuals with dementia.

In the format we have created (box 1), between eight and 10 key events are drawn from a traditional life story and each is recreated as a concise sentence with an accompanying sensory experience. Chronological order is maintained. In a second format (box 2), one specific memory (perhaps a favourite, memorable event) is retold in 8-10 sentence/stimuli pairs. Reggie*, for example, has a story about how his passion for art began with winning a school competition. In both cases, an identity-reaffirming narrative is told through sensory experiences.

Most families have chosen to start with a traditional life story, from which one or more sensory stories are then developed. But where the dementia is more advanced, families may choose to start with the sensory format, given its non-verbal emphasis.

Involving people with dementia in life story work is complex (McKeown et al 2015). The

A ‘sensory story’ is a concise narrative in which each section of the text is partnered with a relevant sensory experience, each story typically targeting a broad range of senses. Story experienceers can engage with the narrative through the text, the stimuli, or both; no part has dominance. Individuals with limited understanding of language can therefore be included in story-telling and its benefits for wellbeing and cognition (Grace 2014, Lacey 2006). Sensory perceptions are key to memory formation (Bogdashina 2003) and repeating a sensory experience reinforces neural pathways (Grace 2014, Longhorn 2011). Accordingly, when sensory stories are told consistently over time, listeners’ responses increase (Brug et al 2012, PAMIS 2002, 2006, 2010, Penne et al 2012).

Sensory stories were originally created to support individuals with profound disabilities (Deonairain 2010, Fuller 2013, Grove 1998, Lacey 2006, PAMIS 2002, Park 2004, Taylor 2006, Young & Lambe 2011) and have since been used effectively with individuals with a range of needs. This paper explores their application in the field of dementia.

Narrative and sensory interventions

Sensory loss associated with ageing is exacerbated by dementia (Bakker 2003). Individuals with dementia are especially vulnerable to sensory deprivation, as difficulties with communication and mobility create barriers to accessing desired activities (Baker et al 2003). Symptoms of sensory deprivation – irritability, confusion, disorientation, lethargy and hallucinations – are common in later stage dementia (Collier 2007). Providing appropriate sensory stimulation is therefore crucial (Baker et al 2003).

Though common in learning disability services, the use of sensory stories in dementia care is not reported in the literature and appears to be a novel approach. Other narrative and sensory interventions are used with both populations:

- ‘Multi-sensory prompts for communication’ support individuals with learning disability and dementia to transition between activities and experience reduced anxiety (Johnson & Elliot 2006, 2008).
- Multi-sensory environments, frequently used

Rebecca Leighton (top) is a specialist speech and language therapist, elenbi-uk and Bradford District Care NHS Foundation Trust; Coralie Oddy (centre) is a student speech and language therapist and founder of ReminiSense, a project providing group sensory storytelling; and Joanna Grace (above) is a special educational needs and disabilities consultant and founder of the Sensory Project.
sensory approach may result in a genuinely joint endeavour between individuals with the condition and practitioners or carers to identify appropriate sensory experiences as ways other than verbal communication to create sensory stories. Even in the later stages, the person’s responses to different stimuli may facilitate ‘co-production’ of this kind. Harry* and his wife worked together to identify smells that triggered holiday memories. In exploring sun creams, they discovered that massaging his arms with the cream increased his responses—the multisensory, tactile element and the physical actions associated with the event were a stronger connection than the smell alone.

The multisensory narrative may retain its impact through the various stages of dementia as verbal understanding decreases. Marian* and her husband paired a piece of music with a sentence about their 1940s dancing. She described him moving his feet upon hearing the music within the story, as he communicated “I remember dancing with you” without words. Perhaps experiencing the music in the context of his life history was important.

Re-telling a sensory life story as dementia progresses should maintain the familiarity and predictability of the stimuli. Marian reads her husband’s story to him every morning as part of their routine and believes he feels calmer with this familiar topic start to each day.

Sensory life stories also empower individuals with dementia to tell their stories, because they can be told effectively without relying on words. This may encourage confidence in ‘total communication’, strategies using multiple modes of communication which value non-speech forms (Jones 2000) and increase communicative effectiveness in people with dementia (Royal College of Speech and Language Therapists 2013). Telling a story creates opportunities for connecting with others. For example, Mary* (who created a story about her career in the Post Office) wished she had had her story when her children were young, so that she might have shared her memories in a way she felt would interest them. This reflection gave her courage to tell it to her grandchildren despite significant difficulties using verbal communication.

Finally, Edward’s* wife viewed the process as something she could do to help. The shared goal of identifying stimuli provided a purposeful focus. Sensory life stories can empower the individual with dementia and the people around them.

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**Box 1. Sentences and sensory experiences: a story across the lifespan**

“We got married in 1947 and I wore my Royal Navy uniform” (visual stimulus: blue fabric with three white stripes)

“At gymnastics we had to put chalk dust on our hands to use the bars” (tactile stimulus: chalk dust on hands)

**Group sensory storytelling**

Sensory stories can be implemented as a group activity in dementia care settings. Such settings generally utilise various group activities and multi-sensory approaches, but sensory storytelling might address some of the shortcomings of existing approaches. Multi-sensory environments can promote wellbeing by offering opportunities to communicate through the senses rather than language (Pagliano 2008) but they may fail to offer appropriate contexts for the sensory experiences, resulting in a lack of satisfaction and under-use (Jakob & Collier 2014). A sensory story on a familiar topic offers both sensory experiences and a meaningful context related to life beyond the care environment.

Social group activities, such as gardening or baking, have sensory elements and reminiscence therapy exploits multiple senses on the basis that sensory stimuli can trigger memories (Schweitzer & Bruce 2008). However, active participation in these activities may be limited for people with more severe dementia. By contrast, experiencing a sensory story does not require active recall of past events (as reminiscence therapy may) or physical and/or verbal participation (as most social group activities do). Furthermore, sensory stories can be tailored to meet the sensory preferences and cognitive skills of the individuals in the group.

The start of an activity session can be disorientating for someone with dementia; for example, they may have to move to a different area and wait for other group members to arrive, which can create anxiety. On the other hand, the repeated use of a sensory story as a predictable part of a reminiscence or activity session could help to build familiarity and reduce anxiety.

A sensory story on a generic topic such as holidays or celebrations may trigger memories for group members and encourage them to share.

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**Box 2. Sentences and sensory experiences: a story of one memory**

“Walter copied a caption: ‘Fry’s chocolate, delicious and nourishing’” (taste / smell stimulus: chocolate on tongue or chocolate lip balm)

“Painting takes Walter into his own little world of concentration and rhythm” (tactile / kinaesthetic stimulus: rhythmical sweeping of soft paintbrush on forearm or paper)
their own stories and have these validated. Indeed, research has shown that simply being included in the storytelling space supports individuals to be braver, more able to cope with experiences that would usually be challenging, and to feel more connected with those who share the space with them (Grace 2014). This may be particularly important for people living in long-term care facilities who become emotionally vulnerable due to losing links to their personal and cultural past (Chaudhury 2003).

Wildlife in the city: a case example

The sensory story "Wildlife in the City" was written for, and shared with, eight residents of a central London care home who have moderate dementia and participate in weekly gardening group sessions. The story was shared at the start of each gardening session, providing structure and promoting understanding of what would take place. Seeing the sensory stimuli laid out became a visual cue for group members as they arrived. For one group member, wandering behaviour at the start of the sessions appeared less marked.

Specific sensory experiences promoted relaxation and the repetition of these experiences increased awareness and attention. The birdsong at the close of the story was played for as long as all group members appeared fully engaged in the experience. During the first session, it was played for around 15 seconds; by the sixth session, it had increased to over a minute. Group members said they found the birdsong “peaceful” and “lovely”. Observations suggested they appreciated the opportunity to engage in the present moment without pressure to participate or respond in a particular way.

The content of the story stimulated memories and gave rise to conversation. Group members initiated discussion about the smells and sensations they had liked and disliked, which naturally led into reminiscences and sharing of memories with the group.

This example highlights how group sensory storytelling can provide appropriate, contextual sensory stimulation and structure social group activities. This may support communication, interaction and reminiscence, and reduce experiences of anxiety and isolation.

What next?

Although we have only introduced sensory stories with individuals with dementia on a very small scale, observations and feedback are encouraging and they appear to be one way of providing appropriate sensory stimulation for people with dementia.

However, our clinical experiences over the last three years are insufficient to comment on long-term outcomes and are not representative of the range of settings in which sensory stories could be trialled. Wider use and formal research are required to fully explore the experiences and outcomes of this form of storytelling for people with dementia and their carers.

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### Points for practice

*Whatever approach is taken to sensory storytelling, two considerations are essential: stimulus selection and sensitivity.*

#### Stimulus selection

The choice of stimuli is centrally important; careful, person-specific and dementia-specific selection is key. This choice is not necessarily focussed on the progression of sensory development as it might be in supporting individuals with PMLD (although this is a potential outcome which might be explored in research). Rather, it is focused on recall and pre-existing associations, on finding stimuli which are strong memory triggers and which are not distressing or confusing (nor likely to become so as dementia progresses).

Identifying strong memory triggers can be difficult, particularly if the person has limited verbal ability to relate their memories, but thinking creatively tends to get results. Breaking tasks down is a good starting point – if the person liked baking, explore the sensory elements of each stage of baking (stirring or kneading actions, feel of flour, smell of vanilla essence, taste of icing) and observe their responses. This type of process revealed, for example, that using a bicycle pump was a great kinaesthetic experience for prompting Shah* to tell you all about the cycling races he won as a young adult.

An assessment or activity to establish the person's sensory preferences is a wise step, so that the experience is an enjoyable and meaningful one. Is the person calmer with firm or light touch? Do loud sounds frighten them? Do they love sweet tastes? Occupational therapy assessments are often excellent sources of guidance for selecting personalised sensory stimuli; alternatively, tools may be found in Fowler (2007) and Grace (2014).

Personalising stimuli is of course more challenging in group storytelling, but tweaking the experiences to fit each group member is not insurmountable.

Consideration of general sensory features of dementia is equally important. Progressive neurological changes affect the way sensory stimuli are processed and experienced (Baker et al 2003). For example, mirrors and abstract projected images may be confusing (Hope & Waterman 2004). Smells, on the other hand, are likely to be successful stimuli because they are the only form of sensory information to remain indefinitely once encoded (Johnson & Elliot 2006). Readers are directed to Jakob & Collier (2014) for further information.

#### Sensitivity

Sensitivity is essential in all aspects of sensory story work. As in all life story or reminiscence work, there is potential for traumatic memories to arise and the practitioner should be prepared for this. There is also a need to consider how the rather reductive act of condensing someone’s life memories into eight to 10 sentences might be experienced.

Having an example of a sensory story helps to introduce the concept. Great sensitivity is required in discussing likely deterioration in verbal communication and increasing need for multi-sensory, non-verbal supports. Talking about those abilities that might be maintained through sensory stories (for example, continued potential for sharing memories and connecting with family and friends) is a more positive approach.

Finally, storytelling can be viewed as ‘for children’ and it can help to focus on sharing stories rather than being told a story. A ‘story tree’ can visually record stories that arise during group storytelling sessions and become a talking point for visitors and care-givers.

Sensory stories may not be appropriate for everyone and they are not posted here as a replacement for any existing approach. Rather, they are an addition to the toolbox of approaches that can be used to support people with dementia, chosen where it is clinically indicated and fits with the person’s own goals.

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*Names have been changed*
Learning from Japan: social projects with business links

Dementia care practice at home can profit from observation of practice abroad. Rachel Woodbridge set out to discover what she could learn from two social projects in Japan.

Looking across borders to see how other countries are supporting people with dementia may help in developing innovative approaches to care. East Asia is reported to have the highest number of people living with dementia in the world, with prevalence rates of 3.1 million (Prince et al 2015). What can the UK learn from approaches that Japan is taking to support large numbers of people living with dementia?

The UK has already obtained valuable lessons from Japan’s response to dementia. For example, the Dementia Friends initiative (Department of Health 2012), which aims to raise awareness of dementia within communities, is modelled on a similar programme in Japan (Nakanishi & Nakashima 2014).

Another initiative taking off in Japan is a set of social projects of which I had heard from my colleague Professor Nick Tyler. Since I already had plans for a trip to Japan, I asked him to put me in touch with researchers involved in these projects, so he arranged a meeting with Makoto Okada, who works for Fujitsu Laboratories in Tokyo. Mr Okada was able to introduce me to two of the social projects; it is my purpose here to share my experiences of these visits, as some elements may be applicable to dementia care in the UK.

OiwakeDementia Project
The OiwakeDementia Project was set up by Tatsuya Wakano and is located in the small village of Oiwake in Nara Province. Mr Wakano’s vision is about creating networking communities where people with dementia can be valued and connected with others in the village. The aim is for the project to be self-sufficient so people with dementia work and profits are used to continue funding the project and develop services. I visited this project with Nobuyuki Yasukawa, a researcher for NEC and volunteer for the scheme.

The hub or ‘place of exchange’ looks out on the hillside over Nara. It functions as a meeting space, a guest house for people with dementia and families and a place for exchanging information, with a café area providing dementia-related resources.

When we arrived we were greeted by a group of people peeling potatoes and packaging vegetables at the kitchen table. My attention was captured by the way people with dementia and professional carers were working together and supporting each other in this activity. We were soon joined by others who had spent the afternoon outside, planting seeds and collecting vegetables.

To the group’s amusement I asked a man dressed in overalls, “Are you a farmer?” to which he replied, “Carer turned farmer!” Both he and the man with dementia he was supporting talked about working together, building a mutual system of rapport around a shared activity and being part of something meaningful ‘beyond dementia’. Their morning concluded with a trip to local businesses to distribute the products.

The afternoon was spent discussing the future for the project with Mr Wakano and Mr Yasukawa. Down the road from the place of exchange they were building a café attached to a traditional “shukuba” (a historic resting place for travellers), where people with dementia, families and local people could visit and work in the café, serving its customers. Across the way, they were also restoring a plum tree forest that had been desolate for some time. Mr Wakano spoke enthusiastically about how future revenue would also be used to build a community centre for the village.

DAYS BLG, Machida, Tokyo
DAYS BLG was set up by Takayuki Maeda, catering for 10 people with young onset dementia living in the city. The setting differed from the first project; the centre was smaller and tucked into a busy road, being closer into Tokyo. However, the philosophy and daily structure appeared to be in line with the work in Nara. As summarised by Okada et al (2013) “rather than treating people with dementia as simply service recipients, treat them as service providers as well” (p450).

For this visit, Makoto Okada, Nobuyuki Yasukawa and I spent the day at the project joining in with activities. The day began with a morning meeting, where the group discussed activities on offer for the day and organised themselves according to preferences. Activities available were washing cars for Honda at the showroom, packing and preparing food for businesses and restoring the garden. We were invited to help in the garden with a group of six others.

Two men supported each other up a ladder to cut back a tree, another spent the afternoon observing from a chair in the garden and one man supervised our tasks. It appeared the focus was on enjoying the process as opposed to the goal of clearing the garden. As with the project in Nara, staff and service users were indistinguishable, as everyone was working on a shared activity.

Acknowledgements
Thanks to Professor Nick Tyler at University College London and colleagues at Brunel University London, and to Makoto Okada and Nobuyuki Yasukawa for their kindness in introducing me to dementia care in Japan. I am also grateful to the social project managers, Mr Wakano and Mr Maeda, and the people with dementia with whom they work.
After a few hours the group came together and opened a kiosk for schoolchildren to purchase products on their way home. Mr Maeda discussed the importance of interacting with the local residents for creating dementia-friendly communities. Other methods they had of engaging local people included market stalls and visiting local schools to talk about dementia. A man, fluent in English having worked in Los Angeles for a few years, translated and told a story they share with schoolchildren using storyboard cards. It was a moving story about a woman living with dementia, and he finished on a personal note by saying that, although he himself had dementia, “this is not to say I can’t enjoy my life and have new experiences”. The day concluded with tea and cake, and each member of the group reflected on how they felt the day’s activities went, sharing new ideas for the project.

**Evaluating the projects**

**Strengths**

When visiting these projects, it appeared all members were enthusiastic and motivated to take part (see box overleaf). Engaging in meaningful, work-related activities and contributing to the development of the projects seemed important. As stated by Masahiko Sato, a Japanese spokesperson with young onset dementia:

> I hope to contribute to society by participating in volunteer activities. I want others to understand that people with dementia are not a burden on society. People with dementia are not simply people who need to be taken care of.

People with dementia in the UK have expressed similar concerns. For example, Harris and Keady (2009) identified themes of loss, fear and abandonment for younger people with dementia. As someone says in that paper: “I lost everything that defined me as a productive and meaningful man when I had to stop working because of my symptoms” (p3). People diagnosed with dementia are not only dealing with a progressive decline in functioning due to their diagnosis but also negotiating their sense of identity and self over time (Beard & Fox 2008). For some, a strong work ethic may be important; therefore, social projects may be one way of enabling people with dementia to maintain their identity.

**Key issues**

Social projects are not without issues. People who take part should have a role in deciding how revenue is used, which may be difficult given the cognitive impairment associated with dementia. Activities should also be carefully chosen around people’s interests, without posing unnecessary challenges. From the two projects I visited, it appeared that focusing on enjoyment of the activity rather than on goal-directed outcomes made it stress-free. However, meeting required outputs for local businesses could have the opposite effect and result in stress.

It is unknown how widespread these community-led projects are throughout Japan and there is a lack of research to evaluate their effectiveness. As Mr Wakano says: “There were a lot of people who could not wait for the national approaches. So we started from what we could do by ourselves.” What he describes as an “advanced grass roots movement” has triggered other small-scale activities across Japan, but there is little data on them. There is anecdotal evidence, however, that they are in demand: Mr Maeda informed me there is a waiting list of approximately 50 people for the Machida project.

**Applicability to the UK**

**Current UK services**

Many UK-based projects already acknowledge the importance of providing opportunities for meaningful activities. ‘Men in Sheds,’ originating...
in Australia, is one example of a project providing meaningful activities for older people across the UK, but it is mainly geared towards social isolation and relatively low numbers of people with dementia participate (Milligan et al 2012). Nevertheless, qualitative feedback included in the report by Age UK suggests Men in Sheds is valued by those few people with dementia who are involved and their family carers.

The report discusses a sense of purpose and worth associated with being able to sell the items they produce, ‘giving back’ to the project. Art-based initiatives are also gaining increasing popularity in both community and care home settings for people with dementia. For example, singing for the brain, creative arts residencies and museum-based projects provide opportunities for meaningful activities.

Even so, these projects are not yet commonplace and nor are activities of this kind often found in broader services. Research has suggested there are not enough community services that cater for people with young onset dementia (Harris & Keady 2009) where work opportunities may be important. Qualitative research by Bamford and Bruce (2000), evaluating UK services, found that some of them lacked meaningful activities. For example, in an evaluation of a dementia café a person with dementia said “there’s notv wrong about the place, but… you get a bit bored” (Bamford & Bruce 2000, p555). The researchers found ‘choice’ was important as well as providing activities with a sense of achievement.

Funding may be one of the problems. A Men in Sheds project in Nottingham catering for six people per session, eight times per week cost £36,569 in 2010/2011 (Milligan et al 2012). This cost was similar to two other projects and was forecast to rise to £50,289 the following year. Given the well known pressures on funding and rising demand from an ageing population, project development has been constrained.

Developing UK social projects

The ‘OiwasxXementia Project’ and ‘Days BLG Project’ are unique in combining the importance of meaningful activities with acknowledging that businesses can play a role in making them affordable. People with dementia can drive forward the development of their projects and be involved in raising money by engaging in various activities provided by local businesses. So the question for the UK is, can it get businesses to recognise dementia as a social issue they should support?

In Japan, there is a national ‘Dementia Project’ which aims to connect private businesses with dementia as a societal issue using focus groups. Another initiative, ‘Futures’, collaborates with the British Council and includes some engagement from organisations such as NESTA and Accenture participating in workshops to develop social innovations for people with dementia (Okada 2013). The UK has begun to move in the same direction by encouraging businesses to become more dementia-friendly (Department of Health 2015).

Of course, it is important to take into account the ethical considerations around exploitation. Projects would have to take the form of voluntary action with transparency and open discussion of income and expenditure. During my visits people with dementia appeared to be motivated by the fact they were contributing to something ‘bigger’ and able to have a say in how the projects grew and invested their money. But guidelines may well be needed on how similar UK projects can be run lawfully and ethically. Taking forward this model in the UK would require both a top-down push, with government and the private sector getting behind the concept, and a bottom-up push by communities jointly reaching out to businesses. Collaboration by the public, private and community sectors may help to create new, affordable opportunities for meaningful activities.

Conclusion

Social innovation can arise from learning about what people are doing in other settings; therefore, perhaps some of these lessons from Japan are useful for moving forward with dementia care in the UK. I was impressed by the initiative people from local communities were taking to network with local businesses and create self-sustainable projects for people with dementia.

Both projects I visited shared the vision of providing activities that value people with dementia as people, not patients. It was not about treatment but looking beyond the dementia to provide activities that they can enjoy and be valued for.
Truth and deception
While deceptive practice has been shown to be widespread in long-term care settings, little is known about the use of deception in dementia care within general hospitals. Through semi-structured interviews, this research sought the experiences of general hospital staff in order to explore their decision-making processes when choosing whether to tell the truth or deceive a patient with dementia. Staff identified particular triggers that set in motion the need for a response and various mediating factors that influenced how they chose to respond. Overall, hospital staff were reluctant to either tell the truth or to lie to patients. Preferred strategies were ‘distracting’ or ‘passing the buck’ to another member of staff. Clinical and research implications include the need for debating the topic further, implementing staff training on communication and evaluating the impact of these processes.

Lesbian and Gay experiences
The subjective experience of dementia for lesbian and gay individuals is largely absent from the literature. Semi-structured interviews were conducted with ten lesbian and gay individuals with dementia and people with whom they had a significant relationship. Three themes were identified: duality in managing dementia, giving yourself away versus holding onto yourself and relationships as ‘sheltered harbours’. Adjustment processes included decisions around concealment, ensuring safety and the promotion of personhood and couplehood. In line with findings for heterosexual couples, partners had an important role in maintaining the identity of the person with dementia but the results suggest additional and distinct challenges, including experienced and perceived discrimination and heterosexism. In response to these situations, interviewees worked to resist a ‘double stigma’ of dementia and sexuality. This UK study highlights areas for improvement in dementia services including training in inclusive practice.

Music: benefits...
Music is emerging as an effective therapeutic strategy for people with dementia but most of the research to date has focused on institutions. This Canadian scoping review sought to summarize what is known about the role and impact that music plays in the lives of community-dwelling older adults with dementia. The authors concluded that music can reduce agitation, improve cognition and enhance social wellbeing. Elliott M, Gardner P (2016) The role of music in the lives of older adults with dementia ageing in place: A scoping review. Dementia. Published online March 18 as doi:10.1177/1471301216639424.

...and challenges
This paper reports on the challenges associated with implementing and evaluating an innovative pilot music and movement project. While participants enjoyed the sessions and they created the opportunity for social engagement, there was little evidence that this is unique to this type of intervention. Difficulties included matching the programme to the needs of participants, communicating effectively and burdensome paperwork. The authors highlight the challenges associated with last minute, limited funding opportunities. In this case, the evaluation team based in UK and Ireland found that many of the difficulties associated with the pilot could have been resolved with more time for planning and preparation.

Horticulture and gardens
Fourteen people attending an adult day programme were recruited to a ten-week structured horticultural therapy programme. The effects were assessed using Dementia Care Mapping and questionnaires completed by family carers. High levels of wellbeing were observed while the participants were engaged in horticultural therapy and these were sustained following the programme. This Canadian study adds to the growing evidence on the benefits of horticultural therapy for people with dementia who have enjoyed gardening in the past.

Effects of greenery
This research team sought to test the relationship between greenery in gardens and the self-perceived health of older residents with complex needs living in a care facility in Sweden. The effects of greenery were found to be positive and significant, enhancing a sense of being away, affording possibilities to experience the outdoor environment as interesting and encouraging visitation.

Research summaries
The research papers summarised here are selected for their relevance and importance to dementia care practice by the section editors (Hazel Heath and Sue Benson). We welcome suggestions of papers to be included. If you would like to contribute a summary or a short comment on an important research paper recently published, drawing practitioners’ attention to new evidence and key points that should inform practice, please contact sue@hawkerpublications.com.

Evidence for practice/Research news
This section aims to keep readers up to date with research in dementia care and the current best evidence to support practice. We aim to provide a channel of two-way communication between researchers and practitioners, so that research findings influence practice and practitioners’ concerns are fed into the research agenda.

We welcome contributions such as:
• Information on recently-completed studies that are available to readers
• Notice of the publication (recent or imminent) of peer reviewed research papers with practical relevance to dementia
• Requests or offers for sharing research information and experience in particular fields of interest.
• Short comment on important research papers recently published, drawing practitioners’ attention to new evidence and key points that should inform practice.

Please contact Sue Benson (sue@hawkerpublications.com).

Moving into a care home
In order to design a decision aid, these researchers interviewed 20 people with dementia or family carers around the time of moving into a care home. They found that decision-makers balanced the competing priorities of remaining somewhere familiar, family’s wish they remain at home, reduction of risk and effects on physical health of the carer and person with dementia. The person with dementia frequently resented their lack of autonomy as decisions about moving were made after insight and judgment were impaired. Family consultation usually helped carers but sometimes exacerbated tensions. Direct professional support, where available, was appreciated. The authors conclude that there is a need for a healthcare professional facilitated decision-aid. This should detail what might change for the person with dementia and their carer, possible resources and alternatives. This should assist in facilitating discussion with the wider family.

Lord K, Livingston G, Robertson S, Cooper C (2016) How people with dementia and their families decide on new relationships or sexual endeavours in the context of a delirium or at end-of-life. The Journal of Dementia Care. Volume 20 Issue 7 has a special section on person centred care including articles on living positively with dementia, the influence of organisational factors on care, training to reduce antipsychotic medications and Admiral Nursing. Most of these articles were published online last year and have featured in JDC Research Summaries.

Also of interest (see News p8, ‘Peer groups prove their value’): This paper reports on a Social Return on Investment (SROI) analysis undertaken on three dementia peer support groups in South London, to evaluate what outcomes they produce and how much social value they create in relation to the cost of investment. Willis E, Semple AC, de Waal H (2016) Quantifying the benefits of peer support for people with dementia: A Social Return on Investment (SROI) study. Dementia. Published online March 24 as doi: 10.1177/1471301216640184.

Technology
In depth interviews sought to identify how persons with mild cognitive impairment (MCI) related to technology in everyday life. The findings revealed various approaches but a reluctance to adopt video-based monitoring. New technologies required a period of adaptation, particularly when support was not readily available. The authors highlight the need to test the potentials of current technologies such as smartphones and tablets for people with MCI.


Defining restlessness
Restlessness is commonly experienced by people with dementia but remains variably defined and measured. These researchers reviewed the literature for existing definitions and measures of restlessness, identified common elements across existing definitions, assessed fit with relevant theoretical frameworks, and explored the relationship between restlessness and other symptoms in 272 community-dwelling persons with dementia. Three key attributes of restlessness were identified as: diffuse motor activity or motion subject to limited control, non-productive or disorganized behaviour, and subjective distress. Restlessness should be differentiated from wandering or elopement, pharmacological side effects, a (non-dementia) mental or movement disorder, behaviours occurring in the context of a delirium or at end-of-life. The authors suggest that understanding the specific manifestations and components of restlessness can enhance the tailoring of interventions.

Regiera NG, Giltina LN (2016) Towards defining restlessness in individuals with dementia. Ageing & Mental Health. Published online Jan 5 as doi: 10.1080/13607863.2015.1128880

New relationships in longterm care
This study explored the views of relatives and care workers on new relationships or sexual intimacy between care home residents with dementia who were married to another person. Using a hypothetical vignette, interviews were conducted with eight relatives of people with dementia and 12 frontline staff in two English care homes. Similar themes emerged from all the interviews indicating that a light-hearted or non-physical connection between residents was deemed acceptable but the moment it becomes a sexual relationship then decision making becomes more complicated. Staff were inclined to turn to managers for advice and to consider separating residents. They expressed familiarity with distracting residents from situations that were of concern. Relatives were considerate of the difficulties faced by care home staff. The use of a vignette facilitated discussion of a potentially sensitive topic.


Multiple medications
Potentially inappropriate prescribing (PIP) in older hospitalised patients, and particularly those with dementia, is associated with poorer health outcomes, so reducing it is essential in this population. This systematic review identified that multidisciplinary teams involving pharmacists may improve prescribing appropriateness but that more research is required into reducing PIP in people with dementia.


Health professional wellbeing
This literature review examined the psychological factors that influence the wellbeing of health professionals who work with people with dementia. The authors propose that approaches to care and the wellbeing of health professionals are influenced by the characterisation of dementia as a terminal illness that typically occurs in older people. Drawing upon terror management theory, they argue that exposure to dementia patients is likely to promote awareness of one’s own mortality and death-related anxiety. The authors propose that health professionals working in dementia care draw on avoidance to manage this anxiety. Both death anxiety, and coping strategies used to manage this anxiety may influence health professionals’ approaches to care of, and attitudes towards, dementia patients. The conclusions have implications for the training of health professionals providing direct service or consultation in dementia care.


Ageing & Mental Health 2016 Volume 20 Issue 7 has a special section on person centred care including articles on living positively with dementia, the influence of organisational factors on care, training to reduce antipsychotic medications and Admiral Nursing. Most of these articles were published online last year and have featured in JDC Research Summaries.
Why don’t we go into the garden? The Care Culture Handbook


The statistics are shocking – in 2014, in Scotland alone, 53% of people with dementia in NHS long-term care units had not been outside in the previous month even though it was summer, according to the Mental Welfare Commission for Scotland.

The Care Culture Handbook therefore presents a much needed look at why so many people in care environments do not go outside. Ideally, all care providers would use this resource to reassess their care culture with the aim of achieving the top level, described by Carroll and Rendell as ‘relationship-centred’.

The authors’ concept is perhaps a little narrowly focused on care culture alone. They say that “an active garden around a care setting was related to the type of care culture in operation, and not in the design of the garden”.

Both building and outdoor space design can directly affect use, eg indirect access; insufficient sun or shelter; lack of interest and activities; no nearby toilet; insufficient seating; and poorly specified surfaces and planting. Outdoor spaces may even be hazardous for people with dementia if the design fails to recognise their cognitive, visual and perceptual impairments. Building design can also affect garden use if, for example, the only way out is via a fire escape door or people with dementia are housed on upper floors.

However, as Carroll and Rendell rightly point out, even with the best garden, if the care culture is against its use, the scheme will fail. The Care Culture Map which comes with the handbook is colourful, attractive and robust, with clear stages under seven headings. Is it easy to use? The map is large, the text small and the overall appearance ‘busy’ – so it presents some challenges in use, particularly for a round-table discussion. If intended for use ‘in the field’, it would present the same difficulties as any large folding map. The explanatory handbook and map need careful reading for full understanding, so they require the reader’s time and dedication. However, if care staff are willing to take this time, it will tell them a lot about their care culture and how to achieve a positive rather than a negative attitude to accessing outdoor space.

What the hell happened to my brain? Living beyond dementia


Passionate, provocative and compelling, this book held me captive from start to finish and I learnt much along the way. Swaffer, who lives with younger onset dementia, is not claiming to represent the views and thoughts of all 47.5 million people with dementia worldwide, yet she expresses many universal truths and is a powerful advocate.

In a voice that is sometimes angry, sometimes sad, and always determined, Swaffer raises many issues that urgently need to be understood by all concerned with the care and support of people with dementia. Through sharing deeply painful personal experiences, she vividly illustrates the profound social and emotional impact of dementia. She describes, for example, the complicated grief that results from the multiple losses endured by people living with dementia – of abilities, knowledge, memories, employment and too often of friends as well – and exposes the lack of support offered. She talks us through her feelings of guilt about having to rely on others, and how the often used references to people with dementia as ‘burdens’ who can have ‘challenging behaviours’ compound this.

Negative language and myths about dementia are a recurring theme of the book, and Swaffer describes the hopelessness that can result from these, embodied in the well-meaning but toxic advice to “go home and give up”, which she has termed “Prescribed Disengagement”. Swaffer explains how this sets people up to hand over power and control to others and to become passive ‘victims’ or ‘sufferers’, thereby fulfilling the prophecy. She stresses the importance, for all people diagnosed with dementia, of ignoring this route to passivity and despair, and she shares her own proactive strategies for living beyond dementia. Key among these strategies is her writing, for which we can only be grateful.

The book is a mixture of autobiography, self-help guide, textbook and treatise. It includes some of Swaffer’s poetry, extracts from her blogs and presentations and even snippets of her next books. The reader is drawn into Swaffer’s lived experience; she warns us at the outset that some sections and sentences of the book may be repetitive, but this repetition serves only to strengthen and authenticate the narrative. The slight feeling of confusion and discomfort it causes (“Did I already read this?”) in itself provides experiential learning for those of us without dementia.

Swaffer’s writing is convincing and persuasive and makes her a force to be reckoned with in the mission to bring about much-needed changes in the support and inclusion of people with dementia. Highly recommended.

Buzz Loveday is director of Dementia Trainers

Resources

West Yorkshire Playhouse has produced a practical guide to staging Dementia Friendly Performance. Launched during Dementia Awareness Week, the guide follows a series of successful dementia friendly productions at the playhouse which according to the theatre have led to “an established model of dementia friendly performances – a model that has a proven level of success for all participants, and that we are proud to share with colleagues in other theatres.” The foreword is by Wendy Mitchell, who has dementia and says that, although she can no longer follow storylines, she had a great time at a performance of Chitty Chitty Bang Bang at the playhouse. “I hadn’t followed the plot, but it didn’t matter. I enjoyed sharing a wonderful time with the rest of the audience,” she says in the foreword. The guide includes sections on language, selecting shows, involving people living with dementia, and adapting shows for dementia friendly performances, among other things. www.wyp.org.uk and search for “dementia friendly performances.”

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legal for care assistants to 
long as they have been 
assessed. This will free up time 
for registered nurses so they can 
administer medications in 
some care homes but not in others. 
Professor Karen Spilsbury from 
Leeds University’s School of 
Healthcare said: “The guidance 
and review make it clear that it is 
legal for care assistants to 
undertake this enhanced role as 
long as they have 
appropriately trained and their 
competence is regularly 
assessed. This will free up time 
for registered nurses so they can 
engage with residents and 
spend time on other important 
areas of work.”

www.gov.uk/government/
publications/administration-
of-medicine-in-care-homes

The two volumes of Design for 
Dementia are intended to be a 
new reference work for 
architects, designers, engineers 
and planners who want to create 
design environments that are 
suitable for people with 
dementia. It comprises a guide 
for the design of interior and 
 exterior environments, 
accompanied by an outline of 
the participatory research 
projects that informed its 
production. According to Jack 
Couts, of the Liverpool 
Dementia Action Alliance, it 
provides a “fascinating account 
of the EU-funded collaboration 
between architects/designers 
Halsall Lloyd Partnership, 
Liverpool John Moores 
University, Merseycare NHS 
Trust and, centrally, people 
living with dementia and their 
family carers who are members of the 
service users group (SURF)… In 
fact, consumer participation has 
been the heart of the project and 
guaranteed its validity and 
value.” The authors are Bill 
Halsall and Dr Rob MacDonald.

www.amazon.co.uk

A new resource called the 
Role of Social Workers in 
Palliative, End of Life and 
Bereavement Care has been 
launched by the Association of 
Palliative Care Social Workers 
(APCSW). “It sets out clearly 
and comprehensively what 
social workers have to offer in 
palliative, end of life and 
bereavement care,” said Anne 
Cullen, APCSW chair. “It’s a tool 
that will be helpful to all social 
workers.” Jointly produced by 
social workers and people with 
lived experience of end of life 
care, the resource sets out what 
palliative care social work is, the 
role and expertise of social 
workers in this field, and what 
they can offer. It is the result of a 
collaboration between APCSW, 
the former College of Social 
Work and the Making Waves 
Lived Experience Network, 
which said that “ensuring that 
everyone has a good life until 
they die and a good death must 
be everybody’s business. Social 
workers have an important 
contribution to make. This 
resource sets out what they can 
do, and how other agencies, 
employers and commissioners 
can support them to provide 


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Blogs I’m watching by Mark Ivory

Dementia Awareness Week, which ran from 15 – 21 May, inspired 
many of the bloggers on my watch-list so here is a small selection. 
Dr Tracey Williamson at the Salford Institute for Dementia blogs 
about an awareness week event at the Lighthouse in the city, 
where the whole day was co-produced by the local Dementia 
Champions Group and led by Joy Watson who was diagnosed 
dementia in her fifties. Working with Salford University media 
students Liam Funnell and Isabelle Garriock the group produced 
a film which, says Tracey, was “live-streamed around the world on 
the day.” It’s called Living Well with Dementia in Salford and you 
can view it on the blog. “The film shows how local people have not 
let dementia get the better of them as well as steps they have 
taken to keep fit and active,” Tracey adds. “It also shows the 
valuable work of those local services that the dementia champions 
wanted to highlight that work well. Relationships and friendships, 
old and new, are shown as being at the heart of living well with 
dementia diagnosis.” Another positive impact was the promotion 
of intergenerational understanding by involving media students in 
the filming. It’s one thing to talk to youngsters about dementia but 
surely it’s a step up if they can be engaged in activities that include 
people with dementia and their families too.

http://blogs.salford.ac.uk/dementia

Dementia Awareness Week caught the attention of Abigail Ryan, 
learning and programmes manager at the Big Lottery Fund, which 
is good news for anyone with creative ideas in dementia care. Ways of 
helping people to live well with dementia have been an emerging 
theme for the fund’s ‘UK Accelerating Ideas’ programme and the 
subject has been much on her mind, “particularly in the wake of this 
year’s Dementia Awareness Week” she says in a guest blog for Age 
UK. The aim of the Accelerating Ideas programme is to invest in 
innovation, not least the “variety of organisations doing great things 
with people experiencing dementia” such as Learning through 
Landscapes which has already received funding to transform care 
home gardens. So where should we expect the Big Lottery Fund to 
put its money? The blog contains a few clues: “Networks and 
organisations like DEEP and Innovations in Dementia are already 
offering opportunities for engagement, but there’s more work to do. 
Continuously ensuring that practice is driven from the bottom up 
could really start to shift attitudes and behaviours in communities. 
It seems that there’s still plenty to learn about what really helps to 
create inclusive communities too.” In a bottom up spirit, Abigail 
and her colleagues want your ideas about what could make a difference 
for people living with dementia. Know anything that fits the bill? Just 
email abigail.ryan@biglotteryfund.org.uk

https://ageukblog.org.uk

“Well what a manic week Dementia Awareness Week has turned out 
to be,” says Wendy Mitchell, who has dementia and blogs 
under the title “Which me am I today?” The week starts with a visit 
 to “the Kremlin,” otherwise known as the NHS’s Quarry House 
headquarters in Leeds, and the photo of the building included in 
the blog shows that the comparison is apt. Wendy was part of a 
delagation to convince the Department of Health’s dementia policy 
team that it should consult with DEEP groups as part of its plans 
for a Citizen’s Panel to monitor progress on the PM’s 2020 
Challenge. Keeping up the breathless pace she’s back in the same 
building the following week for a discussion about the panel’s 
advocacy group, which she had been horrified to discover had only 
one person with dementia on it. “It always surprises me how little 
people think we can contribute or how we’re the last to be thought 
of as needing to be included,” Wendy comments. “There are many 
people out there willing to speak, but it does appear to be the 
same few of us who do speak out.” But speak out she did and 
Dementia Awareness Week was better for it: “I managed to get 
into print at the local council and CCG and did interviews for the 3 
local radios so it wasn’t a wash out…. The wonderful West 
Yorkshire Playhouse also released its guidance for theatres and I’d 
written the foreword so all in all I think I’ve done my bit to raise 
awareness.” And then there was the week-long “Tweetfest” 
organised by #whywedoresearch which she had agreed to 
participate. “My week hadn’t been a particularly good week ‘head 
wise’, so to see all the kind comments and tweets from people I 
barely knew, and to be part of the conversation, was very mood 
lifting.” So, no, definitely not a wash out!
The BBC’s online Reminiscence Archive (‘RemArc’) is helping to stimulate conversations between people with dementia and their carers in a structured approach devised by researchers at Dundee and St Andrews Universities. RemArc draws on photos, music, spoken word recordings and film from 1940 to 1980 to prompt people’s long-term memories. Dr Norman Alin, from the Dundee and St Andrews computer interactive reminiscence and conversation aid (Circa) team, said: “We have devised ways in which the person with dementia and their carers can again enjoy a conversation by having easy access to a carefully designed structure holding a rich array of reminiscence content.” Because the BBC has made the software freely available, other archives and museums will be able to provide a similar service using their own material. www.bbc.co.uk and search for ‘Reminiscence Archive.’

A new tool to help service commissioners promote the health and well-being of people with or at risk of dementia stresses the importance of the physical home environment as part of the picture. An initiative by Public Health England (PHE) in partnership with others, called ‘Dementia and housing: An assessment tool for local commissioning’, it says local commissioning decisions on health and well-being should be based on an understanding of the following factors: importance of the physical home environment to the health and well-being of people with dementia, their families and carers; contribution that housing-related services and interventions can make; contribution of the housing workforce and what is needed to develop the workforce; and the perspective and housing needs of people with dementia, their families and carers, and the support needed to ensure this is central to decision making. The tool, commissioned by PHE in partnership with Alzheimer’s Society, the Local Government Association and the Housing LIN, can be found at www.housinglin.org.uk

Events

20 July Promoting Continence in Dementia
Dementia Pathfinders afternoon workshop looking at person-centred strategies to promote continence. Go to https://promoting-continence-london.eventbrite.co.uk

7 September Changing the Culture of Care
Sixth Eden alternative conference takes place in Birmingham, considering innovative approaches to change. More at www.eden-alternative.co.uk

21 September Arts and Dementia: Research into Practice
Exploring how research and arts practice can work together for mutual benefit. More information at http://tinyurl.com/2016tandem

22 September Scotland’s Dementia Awards 2016
Glasgow awards ceremony celebrating the work of professionals and communities. More information at http://sda.dementiaisscottland.org

22 September Person Centred Validation Skills: communication that works
Dementia Pathfinders course in Wolverhampton on establishing therapeutic relationships using person centred validation. Same course in London on 20 October. Go to https://validation-skills-wolverhampton.eventbrite.co.uk

27 September Young Onset Dementia Conference
In association with Young Dementia UK this conference, in Birmingham, will focus on services that work well and consider next steps for policy and practice. Details on p17 or see www.careinfo.org

29 September – 1 October Alzheimer’s Disease & Dementia
International conference in London drawing neuroscience experts from around the world. Details at http://alzheimers-dementia.conferenceseries.com

18 October Health and social care provision in Northern Ireland – next steps for reform
Looking at the future direction of care in Northern Ireland as demand increases and costs rise. Details at www.policyforumnimi.co.uk

25 October Policy priorities for social care in England – funding, access and supporting the workforce
Examining next steps for integrating care, issues about funding, and developing the social care workforce. Details at www.westminsterforumprojects.co.uk

1 – 3 November UK Dementia Congress 2016
The 11th UKDC takes place at the Brighton Centre in Brighton, bringing together dementia practitioners from across the country for a wide range of seminars, discussions and plenary sessions. Brochure inserted with this issue or see www.careinfo.org

3 November 7th National Dementia Care Awards
Highlighting excellence in all parts of the sector, the 7th National Dementia Care Awards presentation gala night takes place at the Brighton Centre. Entries open until 9 September. Details at www.careinfo.org

16 November Care England 2016 Conference & Exhibition
The title this year is ‘Mind Matters’ and the conference will look in detail at the Mental Capacity Act and mental wellbeing. More information at www.careengland.org.uk

25 November 18th National Care Awards
Highlighting and rewarding excellence in all parts of the sector, these awards celebrate the very best. Entries open until 9 September. www.careinfo.org

30 November Dementia Friendly Awards
Celebrating the achievements of communities across the UK, this is Alzheimer Society’s third Dementia Friendly Awards. Details at www.alzheimers.org.uk

More information on JDC/Hawker conferences at: www.careinfo.org/events or tel 020 7720 2108 ext 223, or email events@hawkerpublications.com
Following the continued success of the National Dementia Care Awards, the organisers - the Journal of Dementia Care - are delighted to announce that the 7th National Dementia Care Awards will take place during the latter part of 2016 culminating in an Awards Presentation Dinner on Thursday 3 November as a part of the UK Dementia Congress 2016.

“The Dementia Care Awards, now in their 7th year, have proven to be hugely successful in recognising and rewarding those who work in Dementia Care. We encourage all dementia care providers to enter this summer and be part of a fantastic event which culminates in our prestigious awards Gala Dinner.”

- Dr Richard Hawkins, Editor-in-Chief, Journal of Dementia Care

Awards Entries Close 9th September!

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- Dr Richard Hawkins, Editor-in-Chief, Journal of Dementia Care

Gala Dinner table bookings are now open | Contact jessica@hawkerpublications.com

We are delighted to announce that this year the National Dementia Care Awards will be hosted by the fantastic Russell Grant. Russell Grant is a British astrologer and media personality, he has written several books on astrology and provides syndicated newspaper horoscopes. Russell’s first television acting role was at the tender age of ten for BBC TV’s very successful Wednesday Play. He was then signed up by Richard Price, Head of LWT Entertainment and was cast in On The Buses and Please Sir!

Russell’s professional dream came true when given the opportunity to learn how to dance on the BBC’s top-rated series Strictly Come Dancing where he was partnered with World Champion Latin dancer, Flavia Cacace. The popular couple won both critics’ and viewers’ hearts and were nominated for a BAFTA TV Highlight of the Year when Russell was shot out of a cannon as part of their Jive routine at the Wembley Arena. We can’t wait to welcome Russell to the National Dementia Care Awards stage!

For sponsorship opportunities contact caroline@hawkerpublications.com

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