

Dementia Diaries



By Philly Hare, director of Innovations in Dementia and exchange fellow at the University of Edinburgh.

People living with dementia from groups in the UK-wide DEEP network are using their mobiles or landlines (or sometimes 3D printed phones) to record audio diaries. These capture their 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 three selected columnists are Wendy, Keith and George.



Wendy Mitchell reports back on the Dementia Diaries event which took place recently at a lovely Quaker venue in Birmingham.

This 24-hour gathering enabled us all to plan for phase 2 of the project, and discuss tricky issues such as safeguarding, editing and themed reports. Wendy really enjoyed the event: "Dementia is a lonely existence but hearing others, in the same boat, talk about their challenges and successes makes you feel part of one large extended family... The highlights of the meeting for me? The girlie giggles as positive risk-taking was put to the test; the hugs and the laughter; and simply knowing you're not alone."

By positive risk-taking, I assume Wendy means our evening wander round the grounds, which involved slippery, mossy paths and an unexpected stream crossing!



Keith Oliver hasn't recorded a Diary for some time, but he now reports back on his initial thoughts on his recent trip to Geneva to present to the UN Committee on the Rights of Persons with Disabilities.

I like this account because Keith is so honest about his mixed feelings about the impact and success of the mission. He felt throughout "a heavy weight of responsibility" and that, as a person with dementia, he was almost a "gate crasher": the physical disability groups were more experienced in lobbying and disability advocacy. However, Keith concludes that "some initial gains had been made from a very lowly base with regards to establishing dementia on the disability agenda and consequent thinking and maybe action." The report that Keith was presenting can be found at <http://dementiavoices.org.uk/2017/07/taking-our-views-to-the-united-nations/>



One of our newest reporters is George Rook. His first Diary is about a very practical issue – how to manage his many medications by using a dosette.

"In the last few weeks I have made some tremendous mess-ups... if you forget to take those key ones... you really come to a very abrupt and quick jam-full... But this week everything's fine. So I recommend it – talk to your pharmacist."

George also writes a regular blog at <https://georgerook51.wordpress.com>

The Dementia Diaries project was started by On Our Radar and is now part of DEEP, with support from Innovations in Dementia. Find out more and listen to the Dementia Diaries at www.dementiadiaries.org or on <https://soundcloud.com/dementia-diaries>. DEEP is a growing user movement of influencing groups of people with dementia across the UK. For more information on DEEP visit www.dementiavoices.org.uk.

Finally, could you show your support for Dementia Diaries by helping us to transcribe new diary entries? It's important that every diary entry is transcribed to make them accessible to as many people as possible. Just click on <https://dementiadiaries.org/volunteer> to find out more. It's very simple and you can do it just once, or as many times as you can. Thanks so much for your support!

JDC asks...

Our opening debate at the UK Dementia Congress* will discuss this motion: "Research has brought us no closer to a cure for dementia than we were a decade ago, and therefore funding should be switched to researching care and support." True or false?

Recently increased dementia research funding is disproportionately allocated to biomedical cause and cure studies. We cannot put all our eggs into one unreliable basket. The current failure rate of Alzheimer's disease drug trials is 99.6%, with only one of 244 compounds identified during the period 2002-12 progressing to market (memantine) (Cummings *et al* 2014).

Experts state that "few at best" compounds currently in late phase one trials have any chance of being approved by 2025 (Cummings *et al* 2016). Any near future treatment or cure for dementia will almost certainly not be able to reverse neurological damage so would need to be delivered pre-symptomatically, if people are to subsequently live without cognitive problems.

If the side effects of any treatment are similar (say) to those of cancer, some people may be unable (due to frailty of other conditions) or may choose not to receive treatment. Most treatments are currently aimed at Alzheimer's disease and will not help the one-third of people with a different diagnosis.

Given this and that around 5.2% of the global population over the age of 60 live with dementia – amounting to one

new case every three minutes (Prince *et al* 2015) - we must acknowledge there will be many people with dementia in society for years to come.

Over the last 10 years many promising psychosocial interventions have been identified that may improve quality of life, on relatively little research funding. Imagine what could be achieved with greater investment. People living with dementia and their family members deserve this investment for their here and now.

Claire Surr is professor of dementia studies at Leeds Beckett University (proposing the motion at UKDC)

While research has not delivered new drugs in the last decade, I disagree that we are no further forward. We now have genetic handles on Alzheimer's, as well as other forms of dementia, which have often in science proven the starting point for untangling the ball of string of people-focused discoveries. We've seen advances in diagnostics and mapped the atomic structures of Alzheimer's protein deposits, allowing for a new era of drug discovery.

What's more, we've trained more people than ever in

* Starting at 18.00pm on Tuesday 7 November, the debate opens the UK Dementia Congress at Doncaster Racecourse (7 – 9 November)

dementia. We have mobilised a dementia research workforce who are ready to find new treatments, removed competitive barriers and developed international partnerships to make research against dementia a global action.

We know that investing money in research for better treatments will pay off in the long term – we can see this in the improvements made to cancer treatment. In the 1970s, only a quarter of people survived. Today, more than half of people with cancer will survive for at least ten years. But the level of investment is incredibly high – almost £600m was spent on cancer research in the UK last year.

It's only since 2013 that significant funding and internationally co-ordinated activity has become available for dementia research. Collectively between all UK funders, dementia research hovered just under £100m last year. Research has mapped out a timeline to deliver effective new treatments by 2025, and so it's still too early to make a judgement on our progress.

We all agree that dementia needs more funding, especially to support the complex care needs of people living with dementia. But robbing Peter to pay Paul is not the solution.

Dr James Pickett is head of research at Alzheimer's Society (opposing the motion at UKDC)

Dementia needs a complete makeover. We need to move away from the disease model which is holding back thinking, funding and access to resources. And replace this with a way of enabling people to live as well as possible.

The first step is being honest. In Alzheimer's disease, brain cells die and the connections between them are lost. So, what are we talking about when we speak about cure? Dead brain cells cannot be brought back.

As such we need to be



From left: Claire Surr, James Pickett, Arlene Astell, Anthea Innes and Margaret Brown

realistic about what funding for basic science is for. At this time, prevention seems the most promising course of action.

If we accept this then we need to turn our attention to what we can do for people who currently have dementia, either diagnosed or as yet undiagnosed. The disease label limits thinking about what is possible. Dementia is located firmly under "health" which means the response is seen in terms of drugs, doctors, nurses, and hospitals.

The reality is that health care has very little to offer the majority of people who live at home in their communities managing as best they can. Dementia is something you live with for the rest of your life and we need to fully enable people to achieve their potential. This means moving to an approach that supports self-management, participation and exercising their full rights as citizens, as enshrined in the UN Convention on Human Rights. **Arlene Astell is Ontario Shores research chair in dementia at the Ontario Shores Centre for Mental Health Sciences in Canada.**

As a society how can we justify funding a research agenda favouring a search for cause and cure over evidence-based research seeking to provide support and care now? With the increasing number of people with dementia and the associated devastating consequences, many countries have identified dementia as a national priority, and the focus of international dialogue for people living with dementia is on "care over cure". Yet there has been a time lag in

transferring to the funding of research into care.

Where is the moral compass of research funders that they deem it appropriate and proportionate to favour future generations who may be offered a cure (despite the absence of such outcomes from the heavily funded cause/cure research programmes to date), while we have a woefully low funding landscape to support people living with dementia now? Why do we not have increased programmes of funding to support risk reduction, to raise awareness, to promote healthy lifestyles that may negate the still unknown plethora of "causes" of dementia?

Equity in the funding priorities is required. This may require a shift in the mindsets of individuals serving on funding panels of research councils, charities and NHS and local authority commissioners to ensure that research concerned with the care of individuals is not relegated to second class status. And to ensure that we do the best we can NOW for all those living with dementia and the two-thirds of the population who will be impacted by dementia in the coming two decades alone. **Anthea Innes is professor and Coles Medlock director at Salford Institute for Dementia**

Let us consider the variables of age, gender, intellectual ability, diagnostic category, morbidity, socio-economic status, education, mental health and loneliness. Who can really believe in a cure? We might ameliorate or slow progression and increase preventative

activities. Yet cure will not happen in my lifetime, if at all, and we need to stop giving false hope.

As a nurse I have worked for many years with people affected with dementia. I watched a stream of hopeful family members who responded to each miracle cure reported in the newspapers and on television. Faced with a frail, vulnerable and severely affected person who could no longer perform any activity of living, I sought to work with the family, who would bring the information so carefully and hopefully. Now we seem to grasp any straw and the internet has provided a number of new "snake oil" remedies.

Over these years, I have watched people "get better" as a result of meaningful activity, humour, music and human touch. These were not considered cures, but care. So is that hoary old argument about care versus cure being challenged now by research into these interventions? But if we call them "interventions" rather than "care" we fall into the same trap of looking for a simple answer, just as we do when we seek a cure. I prefer to see a person with dementia who has hope and support to live well, not wait in vain for a cure.

Dr Margaret Brown is senior lecturer and depute director at the Alzheimer Scotland Centre for Policy and Practice.

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