

## Dementia Diaries



People living with dementia from groups in the DEEP network across the UK are using 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. The Dementia Diaries project was started by On Our Radar and is now part of DEEP.

This month our columnists show how they use the Diaries for a range of purposes – to express frustration, to explore controversial issues, to educate... and just to share a wonderful moment! This month our columnists share a range of views on accessible transport, dementia terminology – and Marmite!



**Elaine Stephenson is a regular reporter from her own home, but this time she recorded her message at the end of a meeting of the Minds & Voices group in York.**

She explains how they had been talking about the difficulties people experience getting on and off trains with a wheelchair or walkers. "Facilities for getting on and off the train are... horrendous at the moment. So we're trying to put that right as well." They met with somebody from the Department of Transport who wanted to hear the views of people living with dementia. "He was a very nice man" adds Elaine. "If he'd spoke up a bit louder, I could have heard him!"

Since this diary, TPE trains have invited the group to do a "supported journey" from York to Scarborough, on which they will be joined by Bradford FIT group and Scarborough DEEPVibes. Watch this space...

We are hoping that others will use audio diaries as a way of reporting back from their meetings and events, and of sharing their activities with others in and beyond the DEEP network.



**Melvyn Brooks from East Kent Forget-me-Nots reflects on the pervasive use of the word "suffering".**

"Yes, we do all hurt and we're not well with dementia... But I'm not a sufferer.... Suffering is not a word that people with dementia like... We are people living with dementia. Be careful the way you choose your words, please, because... society needs to think about what they say, before they say it."

And with that, Melvyn puts down his phone and sets off to the gym, as he does every day! By the way, there are now over 440 signatories to the Dementia Words Matter Call to Action! You can find out more at [www.dementiaaction.org.uk/dementiawords](http://www.dementiaaction.org.uk/dementiawords).



**Jo Bennett of EDUCATE Stockport, records her diary while listening to a radio programme about the benefits of Marmite for people with dementia!**

"Who knows, I'll let you know if my Alzheimer's disappears!" says Jo with some scepticism. This diary makes me ponder on the effect of the constant media coverage about (often unproven) "dementia cures" which bombards us daily. How does this make people with dementia feel?

The Dementia Diaries project was started by On Our Radar and is now part of DEEP, with support from Innovations in Dementia. In the next issue of JDC I will report back on the 24-hour August gathering of Dementia Diaries reporters, at which plans were due to be agreed for the exciting next phase of the initiative.

*Philly Hare, Director, Innovations in Dementia*

Meanwhile, find out more and listen to the Dementia Diaries at [www.dementiadiaries.org](http://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](http://www.dementiavoices.org.uk)

## JDC asks...

### Now Jackie Doyle-Price has been appointed the government's dementia care minister, what should her priorities be?

**A**mong the myriad areas of urgent need for improved dementia services, I suggest two top priorities: diversity and therapy interventions.

Firstly, diversity. Diagnosis is reaching the mainstream of older people with Alzheimer's disease, vascular and mixed dementia. We now need to improve diagnosis for those who are younger, have rarer dementias or come from minority ethnic or marginalised groups. To do this means raising awareness in society and in professionals of rare and young onset dementias.

It also requires us to address cultural issues in relation to dementia care. Until we provide culturally appropriate services, minority ethnic groups will remain reluctant to seek diagnosis. To encourage change, policy should refer explicitly to issues of diversity.

Secondly, therapy interventions. NHS trusts have skilled therapists who provide services beyond medication, support and social opportunities. Occupational therapists, clinical psychologists, speech and language therapists and physiotherapists have specialist skills that can help people with dementia and families to live well across the dementia pathway.

People with dementia and family members should be able to access cognitive rehabilitation, relationship-centred approaches to advance care planning and assistance

with swallowing difficulties, to name but a few evidence-based approaches.

Such interventions can prolong healthy life, independence and family relationships and help to avoid unnecessary admissions to hospital or care. Policy should name not only doctors and nurses but also allied health professionals.

These initiatives would make better use of existing resources and be cost neutral, but they would make a big difference to people with dementia and their families. **Jan Oyebo** is professor of dementia care at the University of Bradford.

**L**ong-standing goals to improve diagnosis rates and increase research funding in an attempt to discover a cure and new treatment options appear to have largely been achieved. This is important, but can we now focus on "care", the continuing disease trajectory and what can be done to support people, families and communities once a diagnosis has been made?

Having worked in dementia care for over 35 years and now finding myself back in a community-focused clinical role, not an awful lot appears to have changed apart from diagnosis rates and numbers identified living with dementia. Care and services are being reduced as budgets are squeezed and organisational priorities shift. Unfortunately, dementia

services are not seen as a priority and valuable community-based services are being lost.

Despite some positive changes in our NHS organisations, discrimination towards people with dementia appears inherent. This needs to change. Many people living with dementia require 24-hour care and there is no indication this will change for the foreseeable future. A priority is to support those who provide these services to do this better.

The new dementia care minister needs to ask herself why dementia is the most feared disease among the over-50s? Is it because no one appears to “care” in our reductionist society?

As our dementia population increases so do associated health and social care issues. Aged and dementia care have long been the poor relations in research, health and social care. Investment, support and care are required *across* the disease trajectory.

I implore the new dementia care minister to work *with* us and be the one who makes the difference.

**Dr Jacqueline Crowther is Admiral Nurse at Kirkwood Hospice, Huddersfield. Views are the author’s own.**

**G**ood care is the biggest determiner of quality of life for people with dementia. It can ensure support with activities of daily living such as washing, eating and dressing, and that people remain independent for as long as possible. Yet for too long the social care system that so many rely on has been in crisis.

Devastating cuts to local authority budgets have seen the broken system crumble further. It is unfair, unsustainable and needs long-term investment to ensure that dementia is no longer the most discriminated against condition and that people receive affordable and high quality care when they need it.

During the election



**From left: Jan Oyebode, Jacqueline Crowther, Nicola O'Brien, Jill Manthorpe and Matthew Norton**

campaign the “dementia tax” became a key issue. It demonstrated the grip that this most feared condition has on the electorate and how the public cannot bear the idea of such injustice between conditions. However, we need to be clear that the dementia tax is not new. It exists already.

The unfair system forces people with dementia to spend hundreds of thousands funding their own care. People affected have branded the situation a “miserable lottery”, while others have said “tell the government dementia is a disease, not a lifestyle choice.”

A long-term solution for social care must create a fair and transparent division of responsibility between government and the individual in terms of who pays for care. A drawn-out consultation that leads to no resolution is not an option.

Alzheimer’s Society stands ready to help shape these solutions. People with dementia have waited long enough for action and workable solutions and their voices must be listened to if we are to see a health and care system that works. The time is now.

**Nicola O’Brien is head of policy and campaigns at Alzheimer’s Society**

**C**ongratulations minister, good to have you here. You’ll probably have lost count by now of the number of people who have asked you about the “dementia tax” – and when you are going to “fix” dementia care. But you have lots of priorities and so here are some ideas about juggling them and about the knotty problem of having to trade off one policy option

with another.

First, policy, plans, and practice imperatives that are directed solely at dementia may become dated rather quickly if they focus on just this one condition. We’ve learned this through bitter experience over the last two decades but it may be helpful in responding to single claims makers and their pressure.

Second is the temptation to be swept along by cure and “promising” science. The UK has made huge investment in seeking a cure for dementia but this means that more people will ask for yet more money – the machine needs feeding. Some popular newspapers continue to say that cure is round the corner – your scientific advisers should help you sort fact from fiction.

Third, everyone loves an innovation. You’ll be receiving lots of invites to new offices, new clinics and new services (often pilots). But many dementia services don’t get visited; and some are in a fragile state. Don’t forget them.

Last, you’ll hear lots of talk of crisis. Please don’t see the staff in dementia care as the problem – they are generally the solution. Prioritise their creativity, their passion and their commitment – and tell them you know they are doing great.

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

**I**t’s disappointing that dementia has failed to be specifically named on the list of official responsibilities for our new parliamentary under-secretary at the Department of Health. While we expect Jackie Doyle-Price

to lead on dementia, it is unclear what area of her responsibilities this will fall under. Without this clarity, we run the risk of dementia slipping off the national agenda – which would be a devastating blow following the progress made in recent years.

But this does present an opportunity for MPs across the department to work together to tackle our greatest medical challenge – a task too big for one person. If we are to defeat dementia and bring about a life-changing treatment for the people impacted by it, we need a united approach and the new minister’s priorities should include:

- **Enhancing investment:** The government must increase funding for dementia research, with strategic investment in people, projects and supporting infrastructure to grow the research base.
  - **Enabling collaboration:** As Brexit negotiations begin, we must ensure the UK continues to participate in EU research programmes and venture capital schemes, while enabling collaboration with colleagues globally.
  - **Increasing sector support:** We call on the government to support dementia research and the broader medical research landscape through its industrial strategy and future policy decisions, so that the UK remains an attractive place to conduct this vital research.
  - **Join Dementia Research:** Encourage people to get involved with dementia research, to help scientists learn more about dementia and the diseases that cause it ([www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk)).
- We’re eager to see how the minister continues the fight against dementia following the progress we’ve already made.
- Dr Matthew Norton is director of policy at Alzheimer’s Research UK.**