

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 reveal some of the frustrations, losses and fears that can accompany dementia.



Steve Clifford, from EDUCATE Stockport, highlights the panic that short term memory loss can cause:

Yesterday Margaret had to pick up our prescriptions from the chemist... so we drove there, parking the car at the back of the Co-op. We looked around, then walked home. We got about 30 yards from our house and I froze. I just felt sick and panic welled up within me. "The car's gone!" I shouted. "It's been nicked..." It was a horrible feeling – dread, despair, panic. Then Margaret said, "The car's back at the Co-op, you left it there, you numpty." Then it all came back to me. "Oh, yeah," I said, "I remember now. And I'm not a numpty".



Melvyn Brooks, from East Kent Forget-me-Nots, explains the impact of losing his dog:

I had to have my fantastic dog put down yesterday. And I am absolutely devastated. My one and only true friend. My beautiful dog that loved, only loved. I don't know how I'm going to survive. I really don't and... I've got no-one to talk to... I'll never have a dog like him again, ever. He was such a lovely, fantastic, loving, helpful... He helped me in the mornings. He helped me in the day. Just being there with me – cuddling – and having a play. My Max.

(Good news – Melvyn has a new dog now)



And Anne Scott, from Northern Ireland, gives an insight into the challenges of just getting ready to go out:

Tonight I'm in the process of getting ready for a night out at a friend's birthday party... It's that time of the evening when I'm very agitated, I feel like screaming. I have to get ready, though I hate this part of the day. The bath is running, but something is wrong. I can't understand why the tub isn't filling up. I'm really stressing out now. What is wrong? I wash as best as I can in a spittle of water, not enjoying it one little bit. I continue to stare at the water, not being able to work out what's wrong. Why is the water still not getting higher? I think of the time again and decide to pull the plug. Then I see it's sitting right in front of me on the shelf where it always is... I have given up and cry in frustration at myself that I can't remember things, can't sleep properly and can't seem to focus on what I need to do anymore.

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

JDC asks...

Did Chancellor Philip Hammond rescue social care with the measures he promised in his Spring Budget? We ask whether an extra £2 billion and a Green Paper on a longer-term settlement can put social care on an even keel

Further investment of £2 billion in adult social care over the next three years, with £1 billion available for 2017/18, is a welcome step to alleviating short term pressures. But it still falls short of the £1.3 billion immediate pressure on social care calculated by the King's Fund and Nuffield Trust.

Chancellor Philip Hammond's Budget appears to be good news in the short term. While councils are expected to spend public money wisely, there are few apparent measures in the Budget to ensure that this additional funding reaches front-line social care services, rather than plugging gaps in existing budgets.

It is encouraging to hear the government acknowledge the pressures on the social care system, and that it will publish a Green Paper later this year to look at longer-term solutions to support care services for older and disabled people. However, we should be aware that Green Papers do not themselves create a change in government policy, so a sustainable solution may still be some way off. For any long-term solution to be effective, government must fully involve provider organisations in shaping a new direction for adult social care.

Investment in the more advanced Sustainability and Transformation Plans for the

future of the NHS is welcome but social care providers need to be more involved in implementation. Although further details on funding will be made clear, the Budget represents a short-term investment to keep the system afloat rather than a much needed long-term solution. **Colin Angel is policy and campaigns director at the UK Home Care Association.**

It doesn't surprise me that the sector's response to the Budget has been so subdued. Social and healthcare providers are under increasing pressure and while the extra £2bn allocated is much-needed, it is undoubtedly not enough – and we are yet to see convincing moves towards balancing the finance-and-demand equation in the long-term. The government has simply bought some time, leaving us awaiting a Green Paper, which may or may not offer the radical solutions necessary to alleviate these pressures.

We all know what is needed in the short-term. There needs to be a concerted and immediate drive towards joined-up thinking between care providers, NHS trusts, clinical commissioning groups and local authorities, ensuring smoother, more effective transitions between services for individuals with care needs. This should be happening now. I am pleased to see a planned



From left: Colin Angel, Pete Calveley, Vic Rayner, Damian Murphy and Katherine Murphy

commissioning oversight role for the Care Quality Commission in this context, but it will have to have clearly defined aims and teeth.

People living with dementia are particularly vulnerable, generally don't do well in hospitals and deserve joined up solutions in facilitative environments. A feature of our new "10-60-06" dementia care training and accreditation programme is building links that support individuals who need help across disciplines, but it relies on good will and cooperation across professional silos, which needs cementing into place far more broadly.

While conversations around funding are ongoing and the long-term picture remains uncertain, people who rely on social care and healthcare services need us to work collaboratively, today.

Dr Pete Calveley is CEO of Barchester Healthcare.

New money for adult social care is always welcome. But we must also recognise that, in the real world, money generally comes with conditions and caveats, the detail of which is where we need to look to understand how valuable any additional resource is likely to be.

The tone of the Budget speech provided a strong steer linking the additional spend with alleviating pressures on hospitals, and maximising the potential for social care to facilitate quick and effective discharge. This has been reinforced by including the majority of the new funding within the Better Care Fund (BCF), for which the new policy framework has recently been announced.

There is much to celebrate in the new BCF framework,

which recognises the symbiotic relationship between care and health, focusing attention on reducing delayed transfers from hospital and non-elective admissions to hospital, as well as on the effectiveness of reablement and admissions to residential care and nursing homes.

But it will be absolutely critical to ensure that this new zeal for effective management of transfers from hospital does not have a detrimental impact on the experience of people with dementia. There is a danger that "effective" really means "speedier," which is not necessarily a good thing.

The appropriate assessment, support and understanding of the needs of someone with dementia will take time, and both hospitals and care providers should not find themselves in a position where they are under pressure from a measurement system that places value on rapid response over and above "time to care".

New money is great, but people are individual, and we have to keep them at the heart of our future ambitions for integrated care.

Vic Rayner is executive director of the National Care Forum.

The Budget money spread over 400 local authorities over three years is not going to unclog the system. And a Green Paper? You can set standards until the cows come home. It's what you DO with them that makes a difference.

We all need to revisit how we operate. At Innovations in Dementia we believe four key values are needed: "justice" – the rights of people with dementia drive everything we do; "warmth" – this brings an

end the idea of "professional boundaries" when dementia involves daily human encounters not "cases" or "users"; "openness" to growth, potential and a sense of wonder; and "bravery" to challenge the status quo, and to push unshackled innovation.

Let's revisit the meanings of day care; respite (for whom?); long-term care based on the asylums (lots of people under one roof); and "recovery". Dementia-friendly communities will be redundant without dementia-friendly relationships. Let's equip the front line not with tedious workbooks but with a range of practical, emotional and psychological skills.

There are some fantastic examples out there, such as the national network of DEEP groups which are changing lives and offer a resource to lead on policy change, service delivery and dementia learning. Or there's our Getting Along programme addressing both sides of the caregiving relationship and Shared Lives, where people live together in welcoming normalised environments, to name just a few.

Some of these may cost, Mr Hammond, but they are invaluable investments. Your government chose austerity. It wasn't a necessity - let's hope it mothers some invention.

Damian Murphy is a director of Innovations in Dementia.

The Budget's extra £2 billion over three years for social care is welcome, but fundamentally not enough. It is not recurring extra money; it is a bridge to the increased funding already due to come from the Better Care Fund.

The announcement also seemed to imply that the funding depends on action by local authorities where social care shortfalls are causing particular problems with delayed discharge from hospitals. However, as we understand it, there are no formal requirements to that effect.

Local authorities therefore have freedom over how to spend what is effectively their first extra social care funding for years. In practice, we would hope to see them approach the task in a collaborative way, taking into account existing integration initiatives and the NHS's Sustainability and Transformation Plans. The quality of local relationships will therefore matter a lot.

The promised Green Paper will need to be bold in order to find a solution to the funding issue. Multiple past efforts have failed – and what does this initiative mean for the planned introduction in 2020 of the cost cap proposed by the Dilnot Commission?

Ultimately, any solution has to bring new money into the system: we believe risk is best pooled across the whole population and Dilnot's model of "social insurance with an excess" was one viable approach. If the Green Paper focuses instead on protecting inheritances, and does not lead to a true new settlement for social care, it will have failed.

Katherine Murphy is CEO of the Patients Association

Writing for JDC:

Do you have a project or survey to report, or a change in practice organisation or structure which has worked well (or not), and would you like to share this experience with others?

Do you have a strong opinion you would like to express? We welcome letters and contributions that promote discussion and debate about dementia care

Contact the editor, email: mark@hawkerpublications.com