

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!



John McErlane recently used the audio diary to vent his frustrations about dementia awareness:

I'm sitting here, frustrated at the ignorance towards people with dementia, especially in public services. The lack of training is abominable. This has to be addressed.



Melvyn Brooks from East Kent Forget-me-Nots explains his view on the risks of people working when they have dementia:

I like to be proactive and do as much as I can... My door is closing, I need to do as much as I can because of that. I just want it to be much easier for younger people with dementia. PIP [Personal Independence Payments] and back-to-work forms – oh my God! In the media now, it's about nurses with dementia working. I wouldn't want that to happen. Their human rights are being taken away. But in any form of work, if I was an employer, how would you feel if someone killed somebody or accidentally left something out?

Many of the Dementia Diarists helped Laurence Ivlil and Paul Myles at On Our Radar to write an article on designing a dementia friendly website. As the authors state:

People living with dementia do not expect web designers to cure the symptoms, and many people recognise that it isn't always possible to apply each dementia-friendly web design lesson when building a site...[but] by making websites more accessible to a growing group of users who are so often excluded from the benefits that the internet has to offer, designers are not only supporting people living with dementia, but also those with similar accessibility challenges.



In their article Ivlil and Myles explain how key features include content, layout and navigation, colours and contrast, text and fonts, images and using multi-media – and finally, the personal touch. Chris Force gives his perspective:

Being able to talk face-to-face might help – for example, by Skype. People could pick up on body language. They could see that I was still there, and getting my thoughts together – and they wouldn't need to keep prompting as they could see I was trying to give an answer.



We will leave today's last word to Elaine Stephenson from York Minds & Voices – who simply wants to share a special moment with all of us:

I went outside and looked up at the sky. I love the skies. And I saw the most beautiful red sky I've ever seen. And then the cloud covered the moon. I just had to tell you.

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...

Not every dementia book makes great summer holiday reading, but some do. Which would you take down to the beach?

Novels about dementia might seem like a "busman's holiday" for human services professionals or families and people with experience of dementia. But growing public awareness of dementia means that we are quite likely to find a dementia theme in almost any kind of fiction.

This is particularly so in crime fiction where the observant author, employing his or her own finely-tuned detective skills, uses dementia as part of a plot but also a way of contextualising and fleshing out characters and places.

In *White Nights* Ann Cleeves paints a picture of a remote settlement, peopled by the main characters but also past residents. Work in a care centre for older people with and without dementia is a good job, the centre is well-resourced, the residents and day attenders cared for. One man whose immediate recall is limited can remember fragments of the past.

There's no spoiler alert here as I'm not going to reveal what happens. But to me the importance of this plot device lies in the "ordinary" elements it portrays and the picture of good care, by good people doing their best. Of course, the centre manager has too much paperwork but that is pretty ordinary too.

For JDC readers a knowledge of dementia potentially enriches our reading of the novel. The plot and characters are dominant

but we can perhaps understand Cleeves' skill in weaving a story about memories into a book that one might happily take for a holiday read.

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

Running a small arts and dementia charity means making time for holidays can be rather tricky. But if I were going down to the beach I would take *Still Alice* by neuroscientist Lisa Genova which wins hands down for me. Yes, it's a clichéd choice perhaps, due to its popularity, but for me it ticks all the boxes.

It is easy to read and it beautifully captures the inside world Alice is living and how it takes a person from the arts to engage with her right to the end. If you have seen the film starring Julianne Moore and Kristin Stewart I still recommend it. The book provides an insight that I feel is lacking in the film – it does what only books can, it gets you journeying alongside Alice, feeling what it might be like to be in her position.

To deepen one's insight it is also well worth reading Christine Bryden's *Nothing About Us Without Us*. It's a book of presentations by Christine – a long term advocate and person living with a dementia. The presentations are bite-sized and perfect if having a quick read between swims and



From left: Jill Manthorpe, Susanna Howard, Mary Marshall, Clare Morris and John Killick

snoozes is more your vibe.

Finally, being a theatre person, I love reading scripts on the beach and if that's your thing I suggest *The Father* by Florian Zeller. It is a highly skilled piece of work which elevates the playing field - perhaps not quite in the stunning way that *Angels in America* did for HIV / AIDS, but definitely in the right direction. A fantastic piece of work.

Susanna Howard is artistic director at Living Words

I will be taking *Circadian Rhythms, A very short introduction*, by Russell G Foster and Leon Kreitzman on holiday with me this year. Russell Foster is often on the radio (you can hear him on Radio 4's "Life Scientific") sharing his concerns at the extent of sleep deprivation and its consequences.

Foster discovered that the eye is not just about vision. It has photosensitive ganglion cells which take in light to manage the body clock. This issue is crucially important for people like me whose special interest is designing well for people with dementia, but it also has implications for staff and carers.

We know that older people, especially people with dementia, often have a less efficient body clock and they wake more at night and sleep more during the day, which is often particularly hard on carers. This may be because people with dementia can be deprived of bright morning light.

We tend to react with night time activities or the pill bottle, before we have tried providing a room,

conservatory or an outside space where there is lots of bright morning light. Facing east is best. We now know that this light also affects alertness and behaviour control. We also know that every bit of the body has a circadian rhythm as do animals and plants. There is also a seasonal rhythm. I am keen to read this little book and update my knowledge.

Mary Marshall is senior consultant, Dementia Centre, Hammond Care.

Flow My Tears, the Policeman Said is a 1974 science fiction novel by American writer Philip K Dick. The story follows a genetically enhanced pop singer and television star who wakes up in a world where he has never existed. The novel is set in a futuristic dystopia, where the United States has become a police state in the aftermath of a Second Civil War (which is also clearly relevant to current events).

This is not exactly a dementia book but a great read and makes you think about the existential experience in waking up to find that no one knows who you are and you feel under extreme threat from the system. You know the rules that people will follow but have no way to influence them. Does that sound familiar?

For me the key to supporting people with dementia is to learn more about the function of the brain and to try hard to stand in the shoes of the person who is experiencing an altered view of reality. This book brings home the role of colluding

with or denying a person's reality and helps us to think about how we can relate to the feelings a person with an altered reality might be experiencing.

Standing back and using a model of the person such as personal construct psychology, a model which elaborates the experience of validation and invalidation, has proved a constructive and pragmatic way to intervene for me. In a similar way, by entering the world of science fiction, we are standing back and reflecting on human experience through a metaphor for reality.

Dystopian futures explore deep philosophical issues such as soul, mind, sense of self and what it is to be human by encouraging us to stand back and imagine.

Clare Morris is a Dementia Pathfinders associate and psychotherapist

suppose that as a writer you'd expect me to choose some worthy tome. Well, for reading on holiday I'd go for fiction above any other genre, so my nomination is *The House on Beartown Road* by Elizabeth Cohen.

It's based on a real-life situation, and tells the story of an unusual threesome. There's Elizabeth the mother, her young daughter Ava, and her ageing father who has dementia. Elizabeth's husband has walked out on her. The plot is based on how they all shake down together after a rocky start. Relationships and language are common themes.

Much of the playfulness and pathos come from the resemblances and dissimilarities of the very young and the very old. It's an easy read, and you often find yourself laughing aloud. Yet the messages are often profound.

In one of her serious moments the author offers one of my favourite quotes on the subject of laughter: "I think that a sense of humour must be hidden in a box very deep in the brain, where diseases have to search for it. Maybe this is an evolutionary tactic, to keep people going."
John Killick is a writer and poet

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