

# The future of technology in dementia detection and care

Smart technologies will one day transform the detection, care and treatment of dementia, says **Thomas Sawyer**. He looks at what the future holds as artificial intelligence replaces pen and paper

The use of technology in health care is growing as artificial intelligence (AI), mobile and tablet computing and cloud-based systems catch on.

In day-to-day health care, these technologies are deployed with a view to raising care standards and improving efficiency so that resources can be better targeted.

In dementia care, new technology has wide-ranging potential, from improving diagnosis rates to earlier detection and ongoing monitoring of the progression of the condition from the early stages all the way through to late-stage care.

## Diagnosis and screening

Let's start with diagnosis. There is an urgent need to achieve better detection rates for dementia, given that a high proportion of patients even now never receive a formal diagnosis and those who do get one may receive it too late for any meaningful intervention. Diagnosis rates are ripe for improvement through the use of technology.

For one thing, there is a well-established relationship between early detection and better clinical outcomes for patients. Furthermore, there is massive economic pressure: a recent report by the Alzheimer's Association in America put the potential savings of early detection to health care payers in the USA alone at \$7.9 trillion (Alzheimer's Association 2018).

Two types of testing are being developed to speed up detection, namely better

collection of data using physical and neuropsychological biomarkers, and better use of data as a predictive tool. What is required is a much-improved early warning system, where prodromal patients can be identified and directed to the appropriate treatment and monitoring pathway.

There have been significant limitations to screening for various reasons, one being the shortage of clinicians to administer traditional tests like the Mini-Cog neuropsychological test for cognitive impairment. It is also the case that shorter tests like the Mini-Cog may not be sensitive enough to detect the mild cognitive impairment which can be a precursor to dementia.

In contrast to these pen and paper tests, electronic tests have the potential in future to be carried out unsupervised by large numbers of individuals, aided by the widespread availability of inexpensive technology such as tablet computers. This would allow us to make more reliable measurements, for example of cognitive biomarkers like speed of processing and visual memory, using tests that are more sensitive than the traditional testing methods and that are not affected by education, language and cultural biases.

Genetic screening is becoming less expensive and also has a role to play in the early detection of familial variants of dementia. Through the detection of known genetic risk factors, people with

familial Alzheimer's disease or familial frontotemporal dementia, for example, will be able to enter the clinical treatment and prevention pathway early enough to give the best possible outcomes.

But technological progress gives us the potential to do even better. Inherited genetic variants are one thing, but what about the much more common "sporadic" variants that affect people by chance? Artificial intelligence techniques capable of looking at unstructured data, such as medical records, will enable us to spot predictive patterns of data suggesting a greater or lesser likelihood that particular people will develop dementia. At-risk patients can then be identified and more closely monitored for the early signs of the condition.

At the same time biochemical techniques like fluid biomarker assays are becoming cheaper and more widely available. For example, there is promising research that should one day make blood plasma biomarkers available for analysis rather than the more established and much more invasive cerebrospinal fluid assays. Reliable blood plasma tests would be of great clinical



**Smart technologies will offer new ways to detect and monitor dementia**



benefit, although they remain some way from regulatory approval.

When disease-modifying drugs do become available, early detection will be vital. No potential therapeutic drugs now in advanced clinical studies offer the potential to regrow damaged nerve cells, so the earlier the diagnosis, the better the outcomes of treatment will be.

## Artificial intelligence (AI)

Neuro-imaging can be combined with AI to look at an image set generated by PET and MRI techniques and find patterns that are indicative of early-stage neurodegeneration. While potentially highly accurate, these imaging techniques are expensive and unsuitable for screening large populations to detect the onset or progression of dementia.

But there is also scope to employ AI more cost effectively by focusing on cognitive ability rather than neurodegeneration. We have already seen the potential for prediction by examining health records on a vast scale but, at the same time, web-hosted "smart" clinical platforms will be ready to triage people remotely in their own homes so they have less need for face-to-face meetings

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with a health practitioner.

The upshot of these developments will be more efficient use of resources in health care and better outcomes for patients who join the treatment pathway sooner than they would have done otherwise. Earlier diagnosis will lead to more appropriate referrals to secondary care, preventing the referral of patients who do not require treatment and ensuring that those who do are referred much earlier.

Our work at Cognitivity has two components: an innovative test based on the rapid categorisation of visual images by subjects using a tablet computer or smartphone and the application of AI to look for patterns in the resulting data. These patterns can be compared with those of known patient populations to aid early detection of cognitive problems.

Our technology, which is currently being developed for clinical use, has published peer reviewed results (Khaligh-Razavi *et al* 2019) and won an award last year from AXA Health Care and Alzheimer's Research UK for innovation in early diagnosis in dementia. It is designed to be easy to use, fast and sensitive, allowing for the screening of patients in primary health care and for home-monitoring of the effectiveness of treatment and the level of patients' cognitive fitness.

When it comes to the ongoing monitoring of patients, there have been significant advances in wearables and the data collection capabilities of smartphones and smartwatches. By keeping an eye on someone's movement or their heart-rate through widely available yet relatively inexpensive technology it may be possible to predict the onset of health problems, giving advance warning of disease risk and progression (Kourtis *et al* 2019). Such simple and commonly available technologies will have the capacity to raise the alarm

before health crises occur, providing an early warning system that encompasses incident measurement such as falls detection.

There have also been advances in technology to measure voice patterns and detect signs of potential health issues. The general availability of "voice capable" devices has helped, as have new systems which allow vocal interaction and interventions such as talking therapy to improve the quality of life and social support for people in the advanced stages of dementia.

Smartphones are already enabling various types of meaningful assistance, for example in the form of memory aids, mental exercises, navigation software and other applications which can empower people to live without assistance in their day-to-day lives. This is in addition to their making it easier to maintain vital social links through calling, video communication and messaging platforms.

This potential for high resolution monitoring and tracking progress opens the door to the provision of far more personalised treatment than has historically been available. A "one size fits all" approach is becoming outmoded in medicine thanks to our growing ability to fine-tune treatment to individuals. These ideas may sound futuristic, but they are fast becoming a reality and will become the "new normal" in health care. ■

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## PERSPECTIVES



### The truth can be costly, but shirking it is costlier still

■ Mark Ivory is editor of the *Journal of Dementia Care*.

By Mark Ivory

"What is truth?" said jesting Pilate and would not stay for an answer." When the Roman provincial governor apparently asked that question two millennia ago, perhaps he reflected humanity's ambivalent relationship with the truth and the fact that it often sounds harsh to tender ears. We can think of examples much closer to home. Is smoking a cause of dementia, is heading the ball in football, is bad diet and little exercise? Are people with dementia dying earlier because of the government's austerity policies? In every case the answer is disputed, sometimes because we simply don't know enough and sometimes because we would rather not hear the truth spoken.

It is certainly true that people with dementia are dying earlier than they did before. In fact, we all are. Life expectancy has fallen by a year since 2014 but of course arguments rage about the reasons for it. Professor Danny Dorling wrote an interesting blog on the subject recently (see Blogs I'm Watching, p42), in which he asks why "competent, able, intelligent people at the heart of government [chose] to ignore the statistics." When it came to the role of austerity in shrinking lifespans, the government rubbished honest research while Rome burned. Public Health England, a government agency, put much of the blame on winter flu and "slowing improvements" in heart disease and stroke, among other things, probably because the deeper explanation risked incurring the wrath of their political masters.

Facing up to the truth requires courage we sometimes lack. Football has a better excuse than government, but what if repeatedly putting your head in the way of a fast-moving ball really does cause dementia? Gordon Taylor, departing CEO of the Professional Footballers Association (PFA), says his association has "led the way" on funding the necessary research. But a £125,000 research budget looks like loose change compared with his reported salary of £2 million and the PFA's annual largesse of £25 million from the Premier League. It doesn't take a genius to work out that finding a link risks derailing the gravy train.

After an interview with Dawn Astle, whose professional footballer father died with dementia, Alan Shearer said he understood why she was upset. "She had asked for answers and did not get any, and it felt like no one had even been listening to her." Perhaps they didn't listen because the stakes were so high.

Finally, it is worth pausing to consider the impending reforms to the deprivation of liberty safeguards (DoLS), soon to give way to supposedly less bureaucratic, easier to manage liberty protection safeguards (LPS). Once seen as a pragmatic way out of the DoLS nightmare, the mental capacity legislation incorporating LPS appears to have become an object of loathing across the voluntary sector, which says that it will merely replace "one dysfunctional system with another". Why? Because the government refused to listen to successive amendments that would have improved it. The truth can be costly but, as we know so well, shirking it can be costlier still.

# Good morning Alexa: what can you do for me today?

If you believe Amazon, the company's voice-activated assistant Alexa will run your life for you if you let it. But is it true? We asked some people living with young onset dementia to tell us how they use Alexa and whether she is good value

## 'I use technology to make my own life journey'

Having a cognitive impairment or a dementia diagnosis changes your life. I made the decision that I would use technology to make my own journey – my journey and not the system's view of what the journey should be.

We use Alexa in our house every day. She has been programmed with my morning routine, my diary, my favourite recipes, medication reminders, alarms and so on. Alexa also can order basics from my local store by emailing my shopping list to them so that they can put together my order and deliver it to me. I can pay via a secure portal.

We used essential lifestyle planning to develop my morning, afternoon and evening routines and we hope to make these tools freely available to others once we have tested the whole programme. When I respond to Alexa and her wake-up alarm by saying "Alexa, good morning," she responds by saying "Good morning Ron, how are you today?" I can reply by saying "Good" or even grunting; she then gives me the day's date and time, followed by a round-up of the news and local weather. She will remind me to have a shower, then tell me that my breakfast tea is ready and either play glam rock or go to Radio 4 depending on my preference that day.

During the day Alexa plays mind games with me, prompts me at med times, reads books for me, and plays music, on request or pre-programmed.



Left to right: Ron Coleman, Carol Fordyce, Dory

She allows my partner to see me and talk to me where ever she is. We will be having a shower controlled by Alexa installed soon so that I cannot get burned or leave the shower running when I finish.

Our aim is to have an Alexa controlled environment throughout the house that will allow us to continue to live our lives our way. Though the set-up costs can be high for those of us on small budgets, we hope to show that the savings in the amount of time paid carers need to be with us will more than offset those costs.

The future is happening now, and we should work together to ensure that people with lived experience take ownership of that future so that we use technology to care about us and not only care for us. Using technology properly may mean the difference between existing in our illness and having a meaningful life.

*Ron Coleman*

## 'A fantastic gadget, but difficult to set up'

Because I live with early onset Alzheimer's disease, I thought that Alexa would be a good thing to purchase as an aid to my daily living. I paid £69.99

for Alexa and I feel this is a reasonable price to pay for what it can do.

Alexa proved to be difficult to set up, even for my husband and he is quite savvy with technology. There is no way that I myself could have done this due to my Alzheimer's. Instructions were not provided and I could not find any instructions online that I could understand. In fact, we still have not quite mastered it all, in a way that would enable us to make the maximum use of it. The difficulties we have encountered are:

- unable to connect Alexa to our music library on Amazon
- getting Alexa to make a music library for us

I have alarms set up on Alexa to remind me to carry out daily actions. Examples: take medication, feed the dog. I also set up reminders, "do Wiltshire farm food order," "Wiltshire farm foods will deliver today," "Complete Alexa feedback."

My husband has connected Alexa to smart lighting, which was difficult at first but he managed after some time to sort it out. So we just ask Alexa now. Alexa plays music from Amazon Prime Music. Alexa

shopping list is easy to use and excellent. Some of her interpretations of what we say are incorrect but not so often as to be a nuisance.

Alexa helps me to go off to sleep at night using meditation, or relaxing music or sounds of my choice.

I also ask Alexa to:

- tell me the weather and temperature, e.g. whether it will rain today.
- play me ambient sounds for sleep, stop playing in 40 minutes.
- turn off all lights, turn off up lights, turn off ceiling lights.

I am able to ask Alexa anything and I will get answers, which is amazing. She will search and come back with answers always. I bought an Alexa for my 83 year old mum. It has been set up to enable her to phone me using Alexa, if she has a fall at home. She just shouts, "Alexa phone Carol."

I think Alexa is a fantastic gadget that could be extremely useful in many ways. Especially useful for the elderly. The problem is setting the thing up. It would be useful if easy to read instructions were included.

I am fortunate to know some



Left to right: Wendy Mitchell, Howard Gordon, Jacqui Bingham, Agnes Houston

people (living with a dementia) who have had help and this has resulted in the person producing an instruction leaflet which will be circulated to us very soon. I am really looking forward to this.

The full talents of my Alexa are yet to be extracted, but hopefully we will eventually get to use it to its full potential.

*Carol Fordyce*

### **‘Plug in, set the wi-fi password and you’re off’**

Alexa helps me to retain my independence, especially as I live alone in Flintshire. I set alarms for wake-up calls, ask her what the day and date is and the weather. I set reminders to eat and drink, and so on.

When I am cooking something I ask Alexa to remind me to check the oven. What I like is that Alexa doesn’t just set the alarm, she will say what she is reminding you of. If I say I am going out at 10, I ask to be reminded at 9.30 have I got purse, keys, phone, etc.

You can set reminders as a one-off or however many times you like.

Download the Alexa app on your phone and you will get reminders while you are out, for example, if you need to be somewhere at a certain time or your shopping list.

Or she will tell you recipes, play music, do meditation and audiobooks, play quizzes, or help you sleep. All this for £39 and so simple to set up – just plug in, set the wi-fi password and you’re off.

*Dorys*

### **‘Alexa helped calm my foggy confusion’**

I was a tad sceptical about Alexa when it first came onto the market. Because I live alone, I thought I might find another voice in the house disconcerting, so didn’t bother with it. But as time went on I began to hear the positives from other people with dementia.

Philly Hare came to visit me along with Alastair Cox from Stirling University and brought an Alexa with them so I was very fortunate. Alastair set it all up for me – I wouldn’t have been able to do that myself, I don’t think. I would have had to wait for my daughters to be free.

I began to use it for everyday things while I became used to it. For example, “Alexa, what’s the news today’. I didn’t need a reminder for morning medication because I already had that on my phone and iPad and it’s difficult to get used to something new. But then my GP put me on some new medication that had to be taken in the evening. Alexa was perfect for this new reminder.

It really became useful one day when I awoke very confused and foggy. I didn’t trust my bedside clock for some reason and I found myself asking Alexa what day it was and what was the time. Out of the blue I asked her to play me some calming music and she did! It helped the confusion enormously.

*Wendy Mitchell*

### **An enabling device with a long list of functions**

Alexa can be enabling for a person living with dementia, depending on their skills and cognitive ability.

The basic Alexa is cheap. I have one with a screen as I need visual prompts as well as audio which was more expensive. You can set one-off reminders using Alexa or regular reminders using the Alexa app

I use Alexa to remind me to take my tablets and to do my blood pressure, as well as a long list of other things: appointments, play music or even hymns, play audiobooks, shopping list, weather, news, play radio stations, control the lights in my home, translate a word, search Wikipedia, make video calls, make phone calls.

Alexa can be used as an alarm clock: you can choose sound, radio or music to wake you up. With the Alexa app on my phone, reminders come up on my phone when I am out of the house. The ability to make phone calls using voice commands could mean that, if I had a fall, I could call out to Alexa to call a relative.

*Howard Gordon*

### **‘It’s great’**

I use Alexa to remind me to take my medication, to have meals and drink. Also, as a calendar to remind me about events and what to take with me. I play music a lot with Alexa and also games. The reminders are linked to my mobile. It’s great because, if I am not in the house, I am still on track.

*Jacqui Bingham*

### **‘I was excited, but it hasn’t worked out as I hoped’**

I received an Alexa Dot for my 70th birthday in October last year. I was really excited as I’d heard about tweets from people with dementia saying what a great help she was in their day-to-day challenges.

This has not worked out as I hoped. Alexa came in a box with no written instructions. After enquiring, I was told just plug Alexa into electricity and she’s ready to use. It was not so simple.

I followed this and nothing happened. I thought it was broken. I sent an SOS via twitter to discover I needed to use Alexa by name to activate her. This worked but there were still more issues. I was making my questions for Alexa too wordy. It was hit and miss

I think Alexa or something similar would be a great help, but I would need accessible instructions with a video to show how to make it work. In the beginning, someone knowledgeable to set Alexa up correctly for me would have helped.

*Agnes Houston*

The contributors to this article are all members of groups which are part of DEEP – the UK Network of Dementia Voices ([dementiavoices.org.uk](http://dementiavoices.org.uk)). They are also regular reporters for the Dementia Diaries project ([dementiadiaries.org](http://dementiadiaries.org)). Both projects are facilitated by Innovations in Dementia CIC.

# LGBT awareness training: learning from Australia

Allison O’Kelly travelled the length and breadth of Australia to research awareness and care for LGBT people who develop dementia. She found widespread good practice, initiatives and training materials, and much for the UK to emulate

Ever since writing in these pages about “Eve”, a trans woman who developed dementia (O’Kelly *et al* 2015a), I have wanted to do something about the lack of training available for care staff who care for LGBT people in this situation. By collaborating on the case study of Eve I wanted to highlight the challenges she – and the staff of the care home in which she lived – faced when she became confused about her identity.

Eve transitioned later in life and developed dementia in her early 60s, going into a care home when her condition deteriorated fairly quickly. At times she referred to herself as male and questioned her female attributes. This was distressing both for her and the staff who wanted to do their best to care for her.

Currently it is unknown how many people who identify as LGBT live in the UK, although there have been several estimates and it is generally accepted to be in the region of 5-7% of the overall population. They are mostly a hidden cohort, particularly older people who have had to live more covertly through fear of discrimination or being seen as criminal in the past. It is possible that out of the 850,000 people living with dementia, 42,500 to 59,500 may identify as LGBT, which is why awareness and diversity training is so important.

After writing about Eve I discovered some excellent free

online training delivered at the time by Alzheimer’s Australia, now Dementia Australia, and was keen to find out how it was developed. I successfully applied for a Winston Churchill Memorial Trust (WCMT) Fellowship to travel to Australia for five weeks to meet the trainers and learn about the LGBT with dementia modules they deliver.

Travelling to a vast country on the other side of the world as a lone female was certainly daunting, but it was also highly rewarding. I had liaised with another Churchill fellow who was part-way through a similar project in Australia and America and she had given me some useful contacts. I was going to meet people in five different territories and glean as much as I could about the training available when caring for someone who is LGBT with dementia.

## Across the continent

My first stop was Sydney. I had been in touch with Kerry Schelks, editor of the *Australian Journal of Dementia Care*, who gave me a contact for my first meeting at the University of New South Wales Dementia Centre for Research Collaboration. There I got all the background detail I needed to set out on my journey across the continent, beginning with the LGBTI Health Alliance which trains staff in care homes and other settings on the particular challenges of dementia.

In particular, LGBTI Health Alliance initiated Silver Rainbow, which is committed to sharing knowledge and

resources, and promotes a better understanding of the care needs of this group. Care homes and settings that complete the training it offers are awarded a “Rainbow Tick” as a mark of their achievement. I was also introduced to the “Gender Passport”, a brilliant little booklet that is completed once and can be presented by a trans or intersex person to care staff and anyone else who needs it instead of having to continually “come out”.

My next meetings were really valuable as HIV/Aids was newer territory for me. I learned about HIV-Associated Neurocognitive Disorder (HAND), a medication-related pseudo-dementia. Advances in antiretroviral therapy mean that the condition is no longer as severe as it once was, but it is still a persistent presence that continues to compromise everyday activities. Unlike HIV-Associated Dementia (HAD), though, people can recover from HAND.

Then I met Uniting, a faith-based organisation dedicated to the inclusion of LGBT people, which is developing a web-based programme especially for them. This was followed by visits to care organisations which were also notable for inclusivity and which told me about their approach to advance care plans and end of life care.

Next, I travelled to Adelaide where I found out about online training and visited a care home that provided its own training around LGBT and dementia. I called in at the Council on The Ageing (COTA), which is a large

organisation for the 50-plus age group and has a presence in every state and territory of Australia. COTA is now responsible for delivering the Silver Rainbow training, which it hopes will eventually become mandatory both in the care system and beyond. Some Australian firms still do not see it as important, but COTA wants to change all that.

While I was in Adelaide, I met an Australian Winston Churchill fellow who had just returned from the UK, where she had been looking at our services for younger people diagnosed with dementia. I wondered whether she thought we were getting it right – or at least trying to do so.

## Gathering knowledge

From south Australia I headed east again, this time to Melbourne, which I found to be very vibrant. There, I met with a trans rights activist and three other trans women from Transgender Victoria (TGV). I was really impressed that TGV do their own LGBT aged care training and was delighted to discover that one of the women was CEO of an aged care organisation, which has an embedded programme to train staff in equality and diversity. While there I dropped in at a memory clinic and was reassured by its similarity to the UK clinic that I am familiar with in my own working life.

By the time I arrived in Brisbane, I had acquired so much knowledge that I could pass some of it on to Anglicare, another faith-based organisation that provided residential care and care

■ Allison O’Kelly is a Queen’s Nurse and clinical lead for memory services in east Cornwall.



Allison O'Kelly (left) on her travels, pictured with Rev Penny Jones who is married to Australia's first transgender priest

packages. I was introduced to OWLs (Older Wiser Lesbians) and attended a workshop to update the online LGBT training I had already completed.

On the final leg of my journey I travelled north towards the tropical zone. The city of Cairns was as sunny and hot as I had expected and, although I was able to enjoy some downtime, I had lined up an important meeting with a psychologist who provides counselling to people considering transitioning. We spoke about Eve, the subject of my case study, and the distress

## My hope is that the UK government's new LGBT Action Plan will help to bring this country into line with the good practice in Australia

that she felt. One of the topics we discussed was Eve's lack of an advance care plan, in anticipation of the loss of capacity that accompanies dementia.

As it happens I had also written an article for this journal (O'Kelly *et al* 2015b) about the value of documented future wishes and I was able to share this at the meeting. It was a productive conversation because my psychologist colleague is now going to include Eve's story in her pre-transition counselling. I felt that I had really made a difference and given food for thought.

### Much for the UK to learn

My time in Australia was certainly a worthwhile learning experience in which I was able to gather training materials and meet generous and inspiring people. Most of them identified as LGBT and among their biggest concerns were getting older, the possibility of dementia, other people's attitudes and being alone. Although it is an enormous country, the connectivity and network of training around LGBT and dementia is definitely

something the UK can learn from.

Training is available in every state and territory and there is sufficient funding for this to happen. Australia has made a commitment to gender diversity and awareness with most of the trainers I met being openly LGBT, thereby ensuring services get it right in the future. In some ways this has allowed people who identify as LGBT to be more visible, something which is also becoming more evident in the UK as younger people feel more comfortable with being "out".

Most of the Australian organisations providing residential and community care for people with dementia are faith-based and the ones I met were fully committed to LGBT awareness. This included mission statements, the content of job descriptions and induction training. Silver Rainbow training and Rainbow Tick are held to be the gold standard, an equivalent to which should be developed and widely available in this country.

The Gender Passport is a simple, easily produced, once-only booklet, which can be scanned into patient records to

ensure patient dignity. There is also free LGBT dementia online training funded by the government and available throughout the year from Dementia Training Australia. Much of the learning from this training is transferable to all conditions affecting LGBT older people.

My hope is that the UK government's new LGBT Action Plan (Government Equalities Office 2018), which aims to reduce inequality for this group and contains more than 70 commitments, will help to bring this country into line with the good practice in Australia. I learned a huge amount from my visit there and would recommend a WCMT travelling fellowship to anybody wishing to learn about innovative practice abroad. I will always be grateful to Eve and the *Journal of Dementia Care* for starting me on this journey.

My report will be published on the WCMT website later this year and you can read my detailed travel blog at <https://aokwinstonchurchillfelow.wordpress.com> ■

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## Sarah Zoutewelle-Morris: a talented creative artist with remarkable insight

Sarah, who has died of cancer aged 71, was a person who combined unusual talents. She was creative to her fingertips, and combined this with a remarkable insight into process. She worked for many years as a healthcare artist in Holland, and for a period was activity director of a psychiatric care home there.

The fruits of all this work are to be found in her wonderful practical book *Chocolate Rain, 100 Ideas for a creative*

*approach to Activities in Dementia Care* (2011). This is one of the books of which Hawker should be most proud of having published; it is truly user-friendly and person-centred.

Sarah contributed workshops to numerous conferences in this country. There are also a number of articles by her in the JDC archive.

She also wrote a chapter for my book *Playfulness and Dementia* (Jessica Kingsley

2013). The first four pages of that chapter entitled 'Even a Few Scribbles' contain more wisdom about the arts and dementia than whole books on the subject. Amongst the points she made which I have not seen elsewhere is the following; speaking of working with a group:

*Being an artist helped because I was comfortable with, well, being uncomfortable! The creative process is full of wrong turns and failed results... The*

*new situation is often the result of those 'failed' results and 'wrong' turns, and could not have been foreseen at the beginning of the process.*

And she compares this with the experience of individuals coping with dementia.

I have learned from Sarah's husband Rende that she had almost completed a second book when she died and I hope that this will soon be published.

John Killick

Following the modest success of my earlier literary exploits with *Welcome to Our World* and *Walk the Walk, Talk the Talk*, I was not thinking of any further forays into writing, when out of the blue I received an email from a publishing company about a possible new book. It was from Andrew James, a senior commissioning editor at Jessica Kingsley Publishers (JKP), who described *Welcome to Our World* as “an intriguing book” and asked me to think about ideas for a new one, particularly since no other man alive with dementia had written about the experience for a professional publisher.

I was both flattered and interested by this suggestion and discussed it with my wife Rosemary and my friend Reinhard Guss. One of my ideas was to try my hand at writing a blend of diary, essay, script and anecdote, inspired by the example of Alan Bennett, whose books I had been reading. Of course, that was a daunting prospect, but I was determined to create something that was different from other books on the experience of dementia.

I met Andrew in London a few weeks later supported by my friend Nicki Griffiths, who took diligent notes of the meeting and patiently helped me understand Andrew’s concept of the book utilising a “narrative arc”. I read some other diaries, like those of Tony Benn and Alan Clark, not because of their politics but because their personalities shone through. I was particularly glad to have read Clark’s diary because it illustrated the pitfalls of revealing so much of one’s personality!

My next move was to create a timeline from 2010 through to the end of 2017, the period I

■ Keith Oliver is Kent and Medway Partnership Trust (KMPT) dementia envoy and Alzheimer’s Society ambassador. *Dear Alzheimer’s: A Diary of Living with Dementia* came out from Jessica Kingsley Publishers in April.

# ‘Dear Alzheimer’s’: a diary of living with dementia

Then a primary school head teacher in Kent, **Keith Oliver** was just 54 when he was diagnosed with young onset Alzheimer’s. In his new book, a diary of living with dementia, he talks about the experience and all that has happened since

wished to cover as it began with me at a professional crossroads in my life and ended with me sensing the same in my life now with dementia. Starting with my diagnosis with young onset Alzheimer’s and my early retirement from my job as a primary school head teacher in Kent, it covers one of the most fruitful times of my life as I became involved with the Forget Me Nots, Dementia Action Alliance, Young Dementia Network, DEEP and Alzheimer’s Society as an ambassador, among so many other things.

I drew around me a small

band of close friends who I knew would help me with typing the manuscript and giving me honest feedback on the text. From Christmas 2017 to September the following year I wrote a chapter a month, each chapter corresponding pretty much to a year of diary entries. Rosemary was always ready to give me constructive feedback and I also wrote additional pieces for the book, either on my own or with the enthusiastic help of three University of Kent students on placement with KMPT NHS Trust.

I have always kept detailed journals looking back over



Keith in his garden writing his journal. Photo by Jen Holland.

events and concise forward-looking diaries, so the material for much of the book was available to me. But diaries are personal documents usually written only for oneself and I clearly needed to ensure the book was readable and interesting for others. This required taking time out to think around the events and make it more like a reflective journal. I dictated each entry into a recorder, the contents of which were typed up by the friends who had kindly volunteered.

Inspired by reading CS Lewis’ *Screwtape Letters* and a course of compassion focused therapy with a superb psychologist, I started writing letters to what initially was Dr Alzheimer, who morphed quickly into Alzheimer’s itself, the condition which occupies part of my brain. I found writing these to be truly empowering, therapeutic and immensely revealing. It was from these letters that JKP suggested the title for the book.

I had already sent the manuscript to JKP when, in January 2018, my muse reappeared just prior to a conference at the British

## 5 May 2010: Receiving the diagnosis

I was speechless. My wife was speechless. The consultant sensed this, and went on to explain that this was a suggested diagnosis and lots more tests and scans would be required in order for this to be confirmed. He then drew two helpful pictures, showing, as he described it, a healthy 54-year-old brain; and then he drew mine based on the scan – he did try to explain the scan to us but it was difficult to draw sense from it...

The sun was still shining as we emerged from the confines of the hospital. I suggested to Rosemary, “Let’s have a walk on the beach nearby” – a favourite spot of ours to clear our heads and take stock – “and I’ll ring school to get someone to cover my lunch duty.” That’s what we did, and I turned to Rosemary the moment we felt the sand under our feet, and I said, “One door closes and one door will open.” I didn’t know which door that would be.

## 4 September 2010: Life as a head teacher

I did go to the GP yesterday, and not surprisingly, he said, “Really, you cannot continue like this. You cannot continue doing what you are doing at work with all that’s happening to your health, so I’m going to sign you off.”

He took the decision away from me, and said, “I’m going to sign you off for two months, which will be an initial period, and during that time, I think you’ve really got to sit down and think seriously about your future, Keith, and about maybe starting the ball rolling regarding early retirement.”

This is the first time I’ve had that level of conversation, either with him or with anybody... I am not scared of what this all means but I am confused, and 1001 thoughts whizz around in my mind – retire/work, retire/work... dementia... Alzheimer’s... end.

### Sometime in 2011

*Dear Alzheimer's* It is now a year since my last letter to you, during which time we have had a number of encounters with each other. I sense you see this as a conflict; if so, some battles I have won, and in some you have gained the upper hand, but although your victories will leave a bitter taste, they will be short-lived.

You tried to tempt me with the falsehood that retirement would be cosy, but warning signals about boredom flashed in front of me. I know you encourage apathy, and then use this as a weapon to bring about decline. I will contest this with you through remaining busy, active, engaged and involved in projects and challenges I have enjoyed for some time alongside new ones...

Paramount in my mind at this time is my desire to establish a new life which maintains what you are seeking to take from me, which is my identity, my personhood, my place in the world, my humanity. All of these at this time are well out of your reach, although I do sense you stretching out your grasping hands to wrench them from me...*Never truly yours, Keith.*

### Sometime in 2013

*Dear Alzheimer's* This may surprise you but you are actually becoming a force for positivity as you drive me into building up a presence and a constructive role. One area where you and I wrestle is around the use of language. You will never define me and I will never be defined by you. I hate the word "sufferer" and will never accept it. You see me as being the disease rather than having the disease. I am not demented. I have dementia – you don't have me! I am still the me in deMENTia. *Yours insincerely, Keith*

### Sometime in 2017

*Dear Alzheimer's* So you will have seen how many gains against you there have been since you came to reside inside my head. Amongst these gains are improved diagnosis rates; the combined efforts of the Dementia Action Alliance; communities uniting against you as dementia-friendly communities... the Young Dementia Network... and the amazing efforts of so many people allied to DEEP, which weaves a positive route through my diary.... When our relationship began back in 2010, if someone had said to me that in 2017 I would be doing this, and suggested what I would achieve in the years between, I would certainly have grabbed the offer with both hands.

You tell me you are a servant of death, and at some point your master will take me, but it is not in your power to decide when that will be. There is a far more powerful, positive force which will determine that, as shown in my growing faith. As the lights start to dim I do intend to leave the "party" before the last waltz...

*With frosty regards, Keith*

Psychological Society. I had written a talk and wasn't sure how to end it when, the night before, the poem I would write for the conference closure suddenly came to me in the shower. It was written from scratch in 10 minutes. This was an amazing experience the like of which I had never had before and, when it was well received at the conference, I decided it should form the end of the book. It is called *Give me... I will.*

I do feel the book is both introspective but outward-

looking, telling the true story of a person living with dementia in a unique format. It is common in the world of dementia to compare oneself now with one's self before onset. I have tried to do it differently, sometimes illustrating how I live now by making comparisons with yesterday, last week or last month, but not stretching the comparison beyond this because it is not always constructive to do so.

I wanted the book to be totally accurate, open and

*Poem to clinical psychologists, researchers and commissioners*

### "Give me... I will"

Give me myself and I will be me  
Give me an ear and I will speak  
Give me patience and I will relax  
Give me music and my heart will dance  
Give me joy and I will laugh  
Give me a way and I will follow  
Give me a baton and I will share  
Give me inspiration and I will excel  
Give me teaching and I will learn  
Give me truth and I will consider  
Give me compassion and I will care  
Give me identity and I will shine  
Give me attachment and I will engage  
Give me occupation and I will be focused  
Give me inclusion and I will belong  
Give me comfort and I will feel warmth  
Give me love and I will thrive  
There's the evidence, now please do something with it now.  
Thank you.

*Your "professional friend", Keith*

honest, and I felt I could only achieve this by writing it myself. But I was surrounded by a team of friends, all great supporters and encouragers who allowed me to bounce ideas off them.

In particular, I would like to acknowledge the much appreciated involvement of Rosemary, Andrew James, Lewis Slade, Nicki Griffiths, Liz Jennings, April Doyle and Reinhard Guss. ■

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# Placing faith in relationships

**L**ynne Phair's thought-provoking article about Dementia Care Matters (DCM) asks whether our arguments for disruptive culture change in care homes, advanced by our founder David Sheard (2018), are driven by an "evangelical" concern to convert people to our system of beliefs (Phair 2019).

There is certainly a sense that people who experience DCM's culture change programme often become "converts" and passionate advocates of the model. This is because the programme creates a culture of care which meets carers' emotional needs and encourages them to draw upon their own sense of personhood to inform their approach.

For many care staff the idea that their work can be both empowering and fulfilling is beyond belief. In discovering this to be so, they are often compelled to tell others the "good news"; there is a form of salvation! Salvation comes when carers liberate themselves from a malignant culture of care which fundamentally undermines the personhood and agency of both the people living and working there. This means removing the obstacles that prevent people being themselves and meeting one another in meaningful ways.

In Butterfly care homes, which adhere to DCM's Butterfly household model of care, the lived beliefs and values of care staff guide their practice. Perhaps this focus on personal belief gives us something in common with an evangelical religious movement, but it is important to note that the beliefs and values which underpin our approach are secular. Four fundamental tenets of our philosophical stance are:

- an unshakable belief in human potential
- an awareness of the interdependent and essential social nature of human existence

Is evidence-based practice always desirable?

**Luke Tanner** argues for a different approach based on emotionally fulfilling relationships

- a devotion to removing the obstacles that prevent people from being fully human
- an understanding that genuine self-actualisation promotes mutual flourishing.

One could say this stance amounts to a kind of faith, a faith in the social value of people's tendency to actualise their full potential. Perhaps when promoting our approach, it can appear to others that we have placed all our faith in our own model of care. In reality we only value this model of care in so far as it helps care staff to actualise this tendency so people living with a dementia can flourish in their care.

We believe that the current obsession with evidence-based practice and its uncritical adoption of positivistic research methodologies can actually contribute to a malignant culture of care. The epistemology underlying these "evidence-based" methodologies makes a number of debatable assumptions, such as:

- there is an absolute hierarchy of knowledge and only the expert elite know how to acquire "real knowledge" and apply it
- direct subjective experiences are too unreliable to have value
- human beings' achievements can be standardised into invariant mechanistic procedures
- logic, reason and objectivity are superior to feelings and emotions
- it is possible to conduct inquiries free from subjective influence, i.e. to be impartial and objective
- lack of empirical evidence is grounds to rubbish alternative forms of knowledge.

This technocratic positivism functions to alienate staff from the very qualities and capacities

that must inform person-centred practices and replaces them with "outcome research", "clinical audits", "empirically validated treatments", "systemic reviews", and "randomised control trials". For most staff these are alien managerialist concepts that are largely incongruent with their actual experience of caregiving and the values that underpin their practice. For people living in dementia care, they often fail to promote the emotionally fulfilling relationships they need to sustain a positive sense of personhood.

Clinical models of research tend to present "evidence" in the same terms as the physical sciences. Within this paradigm person-centred practices are often framed as treatments, techniques or interventions. In contrast a person-centred model of research tends to frame person-centred practices in terms of relationships and recognises that relationships are physiological events as real and as potent as any pill or drug. It rejects the notion, however, that human relationships can be reduced to a set of variables that can be separated, measured or controlled. Rather than attempting to remove subjectivity from inquiry to get to "The Truth," we place people's experience at the heart of inquiry to discover the kind of truths that people actually live by.

Those who demand to see the evidence base for a given person-centred practice before recognising its validity are forgetting an important fact, which is that their own wellbeing and personhood are mostly sustained not by validated treatments or interventions, but by the people they rely on in everyday life, be it a colleague, friend or partner. They do not demand to see the evidence base for the efficacy of

these relationships before trusting in them.

Lynne Phair is right to remind us that some forms of affectionate touch can involve risks for staff and residents. There is currently, however, a far more prevalent risk, the risk of no contact at all. In protecting people with dementia from invasive or hostile physical contact, care providers can end up depriving them of any meaningful contact at all. This kind of deprivation is just as harmful as any other form of abuse.

To address both risks, participants in our "Being a Butterfly" training programme attend a one-day workshop on the role of touch in dementia care. While considering touch in the context of consent and safeguarding, participants can also reflect on the role touch plays in supporting relationships, personhood and wellbeing as well as discussing the risks and benefits associated with different forms of touch.

For those who have a stake in a more empirical approach, our "evangelical" approach with its faith in people's lived beliefs will be extremely unsettling. After all, it is to do with the question of where real power and agency lies. Is the key to great person-centred dementia care in the hands of a group of detached experts who produce an "evidence base" or does it lie in each and every one of us? Thousands of dementia care staff across the UK, Ireland, Australia, USA and Canada passionately believe in DCM because we have placed our faith in them and they have discovered for themselves that this faith was not misplaced. ■

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