

# Dementia Newsletter

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The Editor welcomes contributions and letters for publication in forthcoming issues.

## Chair's Letter

Dear Readers

I find this a very odd letter to write, as usually a letter is addressed to people you know – not to a virtual group!

The purpose of writing is also a little vague. Revd Dr Albert Jewell does an amazing job of putting this Newsletter together and I look forward to receiving my copy which always contains some surprises. So I write to commend the contents of the Newsletter to you, and to urge you to use what you read to encourage and resource others in this vital work.

I recently spoke at an event and alluded to some material that I last used in the early 90s. What startled me was that, to most of those at the conference, this was new material. I'm sure that I've written about this here before. But why is good care of those people who live with dementia still such a well-kept secret? What do we need to do to get the message there?

The age profile of the churches shows us that more are in the 65+ age group, and my church is beginning to do something to acknowledge loneliness, especially among older people. But suggesting a church policy to help those who live with dementia and their carers seems one step too far.

This is beginning to sound like a rant! But perhaps it is time that we were more insistent about the importance of good care, and especially good spiritual care, for those who live among us with dementia. So please share the resources, email selected bits to friends – maybe your minister or pastoral team. Get the message out there!

Happy reading.

Revd Dr Margaret Goodall

## News

Press reports on 26 April of research led by the University of East Anglia featured the findings of a possible link between dementia and the use of tricyclic antidepressants such as amitriptyline, prescribed for pain relief and help with sleeping, and paroxetine (Seroxat). This was the outcome of an investigation of GP records of more than 40,000 people over 65 with dementia and nearly 300,000 without. Those on the drugs between 4 and 20 years were 3% more likely to have been diagnosed with dementia, although the researchers stopped short of claiming a causal connection. Antihistamines for hay fever and gastrological drugs were given a clean bill of health.

Scientists have identified the molecular mechanism that leads to the death of neurons in amyotrophic lateral sclerosis (also known as ALS or motor neurone disease) and a common form of frontotemporal dementia. ALS is a progressive and terminal disease that damages the function of nerves and muscles, affecting up to 5,000 adults in the UK at any one time. Frontotemporal dementia is a form of dementia that causes changes in personality and behaviour, and language difficulties. A common characteristic of ALS and frontotemporal dementia is the build-up of clumps of misfolded RNA-binding proteins, including a protein called FUS, in the brain and spinal cord. This leads to the death of neurons, which stops them from communicating with each other and from reaching the muscles. Writing in the journal *Cell*, the researchers from the University of Cambridge and University of Toronto also identify potential therapeutic targets for these currently incurable diseases.

In mid-May it was reported that Sheffield University had received £150,000 funding from Alzheimer's Research UK to facilitate the two-fold study of the causes of the condition, looking at the links between oxygen starvation in the brain and dementia, and identifying which infections and injuries contribute to the development of Alzheimer's.

21-27 May was Dementia Action Week which brought good exposure in the media and much local activity. The Guardian published a special 8-page supplement on 23 May produced by Mediaplanet. Introduced by Jeremy Hughes, CEO of Alzheimer's Society, it included (amongst others) articles on the positive contribution that outdoor activity can give to those living with dementia; the need to challenge society's tendency to label and stigmatise those with the condition; how to reduce the risk of dementia by staying active, challenging your brain, being social and managing stress; protecting the wellbeing of carers; how a good care home can

relieve the anguish of dementia; and an affectionate and insightful account by David Baddiel of his father's journey into Pick's disease.

On 13 June the UK media reported on a new study of almost 9,000 civil servants, published in the *European Heart Journal*, which found that 50-year olds with blood pressure readings of more than 130/80 had a far greater chance of developing Alzheimer's disease in later life. Currently, around seven million Britons whose blood pressure exceeds 140/90 are recommended by GPs to take medication to control it, but NHS watchdogs are now considering bringing the threshold down further, in light of these findings. Almost half of the adult population in the UK would then be eligible for such drugs. There is already an acknowledged association between vascular dementia and high blood pressure.

On 3 July the *Guardian* included two items concerning the contribution of technology to dementia care. In the first, Jules Montague reported on the research carried out by Jan Wiener and his team at Bournemouth University's department of psychology into the difficulties people with dementia have with 'wayfinding' (navigating in physical space). It seems that such difficulties can emerge decades before Alzheimer's is diagnosed and that older people are slower at learning routes (and rely more upon external landmarks) than younger adults. VR (virtual reality) can help simulate and then change care home environments to be more helpful to residents – though making changes can also exacerbate difficulty. Wendy Mitchell, diagnosed with early onset dementia at the age of 58 (see the review of her book in this newsletter), is interviewed and has trenchant views based on her own experience regarding the contribution that design can make to mitigate depth perception problems citing the shiny flooring in a new shopping arcade in Leeds (which I can endorse! Ed.) and abrupt changes in surface colours such as a black doormat appearing to be a hole. In his editorial comment on the growing use of 'robo-carers' in Japan and experimentally in Southend, John Harris recognises the contribution they can make to offset the dearth of human workers but doubts they can match the true empathy only the latter can provide

On 5 July Ivan Koychev, a clinical lecturer in old age psychiatry at the National Institute for Health Excellence (NICE), spoke about his study 'Prevent' which explores to what extent lifestyles of people aged 40 to 59 are related to the development of dementia, which can start up to 25 years before the first symptoms, so as to identify potentially modifiable risk factors.

Whilst scientific studies into the links between alcohol consumption and dementia clearly demonstrate that heavy drinkers are more likely to develop dementia, there is conflicting evidence in relation to low and moderate consumers. The results of a study by British and French scientists, reported in the British Medical Journal and discussed on the BBC Today programme on 2 August, appear to show that those people who are total abstainers when aged 50 are 45% more likely to develop dementia than moderate drinkers; they are also more likely to suffer strokes or heart disease. However, without further research the medical authorities are unwilling to change their advice that all levels of alcohol consumption are likely to increase the risks.

Quite by accident on 16 August I came across an on-line reference to a possible wonder cure for Alzheimer's and other dementias. It was posted by Martin Reilly, a US teacher whose wife, also a teacher, had developed early onset rapidly developing dementia. Whilst visiting a possible care home for his wife he met a very impressive centenarian resident who told him that dementia was unknown in the area of North India from which she originated. Discovering that she cooked her own meals he felt that there might be a secret in her diet which turned out to be based upon coconut oil and various plants, herbs and spices. Seemingly, after 21 days using the diet it appeared that his wife's dementia was halted and even reversed. It is claimed that the diet might restore the ability of neurones to convert glucose into energy in dementia subjects and a clinical trial was initiated amongst volunteers and a control group. Reilly is of the opinion that the big pharmaceutical companies will do anything to suppress such research because they want to protect the sales of the partially helpful drugs they have developed. Checking with the Alzheimer's Society they say that the research has been halted and that those with dementia would be unwise to adopt a coconut oil based diet without much more experimental evidence of its benefits.

On 8 September the Yorkshire Post reported on a trial study carried out by Anglia Ruskin University's Cambridge Institute of Music Therapy Research in collaboration with Saffron Walden's Saffron Hall concert venue. 'Together in Sound' brought together those living with dementia for weekly session of playing and singing. Participants completed a rating scale which revealed 100% enjoyment and a slight increase in mood and memory. Helen Odell-Miller, director of the Institute said that ultimately they would like to see the project rolled out more widely.

On 19 September, the on-line Daily Mail published a front-page report linking air pollution with increased risk of dementia for thousands of city-dwellers in the UK.

The on-line version of the paper puts this increased risk at 40%. This is based upon a study of almost 140,000 people aged 50 to 79 registered with GP practices in London which followed their health records from 2005 to 2013, during which time 2,181 persons developed dementia. The results were published in BMJ Open by researchers from Imperial College and Kings College London. This was much more frequent amongst those living in areas with the highest levels of nitrogen dioxide and microscopic particle PM25, which are by-products of traffic emissions. The newspaper rightly says that it is likely that air pollution is only one amongst many factors that may contribute to the risk, and Alzheimer's Research concurs with this. A recent Canadian study has produced similar results.

In the journal Nature in September a study by Darren Baker and colleagues at the Mayo Clinic in Minnesota reported how mice with a genetic form of dementia accumulated senescent cells in regions of the brain involved in memory and cognition. However, when the mice were treated with a modified enzyme to clear the cells as they appeared, the outward dementia symptoms disappeared. Further work is required to test whether these findings translate into human patients. Scientists at the University of California reported in September a connectivity between parts of the brain responsible for memory formation and storage. Ten minutes of light exercise daily showed an improvement in 36 young volunteers as compared with a control group who did not exercise. Project leader Michael Yasser suggested that 'An evening stroll is sufficient to get some benefit.' It remains to be seen whether the same will apply to much older people.

At the end of September the BBC announced the launch of a website, BBC Music Memories, to trigger memories in people with dementia, containing snippets of around 1,800 musical tracts, including the biggest songs from the last 100 years, TV and radio theme tunes and the most popular pieces from 20 classical composers. Further information can be found at: <https://music.memories.bbcrewind.co.uk/>

On 6 October the Guardian's North of England Editor featured the recently opened 63 room Five Ways care home in Bingley which is the brainchild of Damian Holt. The entrance drive has been transformed into 'The Street' and contains the Seven Dials barber shop, Bingley grocers and post office, whilst the interior boasts many period pieces as well as 'memory pods' such as a cinema room, bar and a 1960s formica kitchen. Holt is quoted as saying: 'What we do here is embrace an era many of the residents think they are living in and make it as stimulating as possible'.

On 13 October the Guardian included a special supplement, titled 'Train Your Brain: Find focus in the digital age'. Amongst others, an article by Professor Gary Small of the University of California explained how, as we age, brain cells that normally fight off infections and repair tissue can begin to attack healthy brain cells, leading to cognitive deficits and diseases, including dementia. He recommends 'four daily steps to a younger smarter brain' comprising physical activity, mental exercise, stress management and healthy diet.

During October Channel 4 has been running a second series of its documentary on four year olds, 'Old People's Home for four-year-olds' featuring an age-gap experiment at Lark Hill retirement village near Nottingham. It concentrates on the burgeoning friendships that developed between very old residents and a group of 3-4 year-olds, their sheer joy in being together, and the impact upon memory and well-being in the case of those older people living with dementia. We shall hope to include a review in our May 2019 issue.

In mid-October St John's College Cambridge posted a press release relating to an article published in the journal PNAS regarding an important finding from research carried out by scientists in the University's Department of Chemistry in conjunction with Lund University in Sweden. Although there have been some 400 Alzheimer's clinical trials this is the only one to have specifically targeted the pathogens that might cause the disease which were found to be clumps of proteins called oligomers. Professors Michele Vendruscolo and Christopher Dobson believe that this discovery could eventually lead to the development of new drugs to treat dementia.

## **Reviews**

### ***Yoga for Dementia by Tania Plahay, 260 pages, Jessica Kingsley Publishers, 2018***

Jessica Kingsley are to be congratulated on the volume and quality of books concerned with dementia they have published over many years. Not only have they produced three books that I have edited but I have sought to have reviewed as many as possible in our Dementia Newsletter.

Tania Plahay's book is the most recent. Beautifully produced and illustrated (with a added link to a number of video resources), the publication is intended for people with an early diagnosis of dementia, and family and professional caregivers, not least those working in nursing homes as activity coordinators and the like. Indeed, the author suggests that all who read the book can benefit from the suggested exercises.

It is important to read the Foreword and Introduction because these endorse the high qualifications and wide experience of the author and allay concerns that readers may have concerning physical or mental constraints about such exercises: 'They are gentle, safe and true to the origins of yoga'. Moreover, 'You do not need to be a "spiritual person" to be a yogi' (i.e. practitioner). Plahay is keen to demystify yoga practices and show that they can be appropriate for people at all stages of dementia. The book has arisen out of a project funded by the Foundation of Nursing Studies and the Burdett Trust for Nursing. Working with a dynamic nursing home manager and backed by a multidisciplinary team of experts, the project showed a positive physical effect on the residents by providing meaningful calming, simple and beneficial activities. Breathing exercises, gentle physical movements and guided relaxations are examples. The author hopes now to roll out her programme in a large number of homes.

Plahay recommends that readers may wish to skip to sections of particular interest to them, guided by an ingenious use of 12 symbols relating to the 'level' of exercises and their application to specific needs such as the promotion of better sleep or remedying stress and anxiety. The first three chapters on What is Yoga?, Types of Yoga and Yoga Philosophy and Principles are of great interest but not for the faint-hearted reader. The subsequent chapters (4-14) deal with the nitty-gritty providing a tool kit specifically related to working with people with early dementia diagnosis or mild cognitive impairment, the different stages of dementia, stimulating the senses, and anger management – which can be a real challenge both for people with dementia and their carers.

There are of course many activity coordinators working in care homes. They will certainly find many helpful suggestions they can put into practice. They may however feel daunted by the sheer range and depth of this book and for sure feel the need for further training. However I am much in agreement with Professor Martin Green, CEO of Care England, who warmly endorses this book and writes: 'I have been fortunate enough to see yoga in action in care homes, and I know that it can make a real difference'.

Albert Jewell

***Somebody I Used to Know by Wendy Mitchell, 300 pages, Bloomsbury Publishing, 2018, £16.99***

As I began to read this Sunday Times best seller book for review, I had the strange feeling of having read it before – which was solved when I suddenly remembered that I had listened to the excerpts read in Radio 4's book of the week just a few months ago and which had had a great impact on me and it seems many other listeners. It is one of an increasing number of publications in which persons with (usually early-onset) dementia have been willing to tell their story movingly and honestly, counter-balancing the prevailing culture which has tended to give the impression of writing-off those with the condition as no longer of any real value.

Wendy Mitchell is a prime example. Following three falls whilst out running she sensed that her legs and her brain were no longer 'talking to each other'. Because before these accidents she had already felt 'fuzziness' of mind she did not believe that her symptoms were the outcome of brain damage from her falls, rather the result of a condition that had already started in her body. Experiencing deep fatigue and losing manual dexterity, she was referred to the hospital where she had previously worked, and a stroke but not dementia was initially confirmed. Eventually diagnosed at the age of 58, she was compelled quite soon to give up her demanding career as a non-clinical team leader in the NHS and her ability to drive, cook and run – all aspects of her cherished personal independence. Many other challenges and diminishments were to follow though there were also gains such as the ability to live in the present, the joy to be found in taking time out in one's pressured lifestyle, and discovering the value of reading short stories as against long novels. It is fascinating how, throughout the book, she conducts conversations between her present dementia-affected self and her 'former self' as she remembers it from earlier stages in her life.

Mitchell's account of her journey is of great value to anyone diagnosed with dementia and to their carers, whether family or professional. Determined to fight her condition, as a naturally resourceful woman who had brought up her family on her own, she employs every practical, psychological and electronic device that she can muster, whilst remaining realistic that there is a limit to the extent that she can 'outsmart' dementia, and indeed remember how to activate the vital electronic aids. Most importantly, she is swift to join an affirming local dementia support group and to approach the Alzheimer's Society to become a dementia friend, champion and ambassador and to participate in a succession of research projects to ensure that the voice of those with dementia is properly heard and hopefully to benefit others in the future. Her struggles to travel independently to conference venues and

to make carefully scripted speeches at them are at times agonising but leave the reader filled with admiration.

The responses she receives sometimes display insensitivity on the part of professionals as in the case of her health service employers, who think that they are being generous in hastening the end of her career rather than finding continued work for her, or in the unfortunate choice of words by some doctors with their deflating effect, and supremely in the withdrawal of her Personal Independence Payment because she appeared to cope so effectively! Other people tend to think that she cannot possibly be demented because she appears to be doing so well but are mostly grateful when she explains that they need to understand that she is only in the early stages of her journey into dementia.

Mitchell is fully aware of the pressures that caring for someone with dementia places upon their family. Her grown-up daughters Sarah and Gemma are very supportive but Mitchell, sensitive to the unwelcome reversal of the mother-child relationship, insists on living on her own, believing that her continuing independence outweighs the loneliness and vulnerability she at times feels. She does eventually move house to be near her younger daughter and partner even though she is well aware that such a move, especially at a later stage of dementia, might prove too disorientating. She also experiences the hurtful 'going to ground' of some former friends and neighbours because they simply do not know what to say to her.

There is no mention of religion in this book. However Mitchell's spirituality is fed by her joy at the world of nature and her inner resilience and her concern for others are simply inspiring. Her testimony should be read by everyone who wishes our society to be truly dementia-aware and dementia-friendly.

Albert Jewell

(The above review has also appeared in *Christians on Ageing's* autumn *Plus* magazine.)

***Trevor Adams 'Developing Dementia-Friendly Churches, 28 pages, Grove Pastoral, Cambridge, 2018. £3.95***

Dementia is understood to be a common condition amongst older people. There is increasing enthusiasm for helping everyone know about dementia and to modify the way they behave so that people with dementia and their families are not disadvantaged by inappropriate and uncaring responses to difficulties which arise from the condition. Membership of churches in the UK includes many older people

and church people have become committed to be sensitive to their needs and to reach out in an informed and constructive way to others who develop dementia.

Trevor Adams was a nurse academic and now is a director of 'Passionate Dementia Care', which offers training and other help to churches and other organisations engaged with people with dementia.

This booklet offers solid information about dementia and advice on good practice, with examples of successful initiatives and a list of useful references. I am less comfortable with chapter 3 'A biblical narrative' covering 'The Just God', 'The social and relational God', 'Jesus' victory over evil'.

I much prefer Gaynor Hammond's more straightforward 'Growing Dementia-friendly Churches' published by Christians on Ageing, and the series of brief notes: 'Visiting people with dementia', 'Spiritual care and people with dementia', 'Worship and people with dementia' and 'Growing Dementia-friendly churches' – all published by Christians on Ageing with Methodist Homes for the Aged (MHA).

David Jolley, MSc FRCPsych, Altrincham

***Spiritual Care for People Living with Dementia Using Multisensory Interventions: A Practical Guide for Chaplains by Richard Behers, 127 pages, Jessica Kingsley Publishers: London, 2018, £14.99***

This small book suggests ways in which spiritual care can be offered to those living with dementia using the senses. But in those few pages it managed to both encourage and depress me. It was encouraging because the author had caught the essence of person centred care and has developed what he calls a 'Dementia Care Protocol' to support and encourage others. But I found it depressing because the call for Person Centred Care that Tom Kitwood wrote about in the late 80s is still being presented in 2018 as a new way of caring for those who live with dementia.

To begin at the beginning, Behers begins where many of us did: going into a care home and being tasked with offering spiritual care to people living with dementia and feeling that 'I don't know what I'm doing!' Behers writes about the importance of relationships, and the difficulty of going in 'cold' and falls back on his knowledge of favourite hymns, finding that he was able to make a connection. This, he says, encouraged him to develop a 'Protocol' that others could use. It offers a voucher code via the publishers to enable key components of this Protocol to be downloaded. Unfortunately this link is not working at the moment and the publishers are currently sending the resources by email to enquirers.

Behers rehearses all the reasons why church ministers seem reluctant to offer the necessary care, from the 'waste of time', 'there's nobody there' comments to the view of society that really it is simply warehousing that is needed. He then takes us through the history of the hospice movement and care of each person being important, with the mantra to 'live until you die'. In dementia-care he sees this expressed in 'awakenings'; times when the person is connecting to what is happening and usually when sensory interventions are used.

Two things I found really useful were first that whenever writing about using church pictures or prayers Behers also gives ways in which other faiths can use their resources. The other was the example of when painful memories were brought to mind by the person with dementia, and how this was resolved. Such reactions can often make those offering spiritual care reluctant to open the memory box.

What I found more confusing in a small book were the pages on what should be included in eight sessions for those in theological education. And I would have appreciated more depth on why the multisensory intervention might open windows for us. The book can be summed up in two of the headings Behers uses: the 'Imperative of Personhood' and the 'Imperative of the caregiver'. All good stuff and well worth a read.

Margaret Goodall

## **Networking**

The Royal Surgical Aid Society has announced that it has rebranded as 'Dementia Carers Count' (<https://dementiacarers.org.uk/>). At the charity's 150<sup>th</sup> anniversary the decision was taken to focus on family carers of people with dementia, who often receive little support at a time in their life when it can be most needed.

Dementia Carers Count (DCC) has already piloted a raft of practical courses attended by husbands, wives, partners, daughters, sons, daughters-in-law, sons-in-law and grandchildren, spanning ages from 18 to 79 years. As well as helping them to better understand the person they care for and to build skills and confidence to see them through the ups and downs that caring can bring, carers have the opportunity to meet, connect and share the load with others experiencing similar challenges.

Carers who have taken part in DCC's pilot courses are unanimous in their support for what the charity is doing. *'The course did me so much good – I am still feeling calm and relaxed...this is probably the best I have felt in years. It's funny how a few days can be so transformative.'* Sarah Churchill, carer.

Alongside the rebrand and at the heart of DCC's vision will be its flagship Dementia Carers Centre, where its expert-led courses and services will be housed in the future.

Claire Goodchild, CEO of Dementia Carers Count said, *'I'm excited about the innovative work that DCC is leading, and about the wonderful feedback we've had from carers so far. Incredibly, there are 700,000 unpaid family carers of people with dementia in the UK. Carers are at the core of what we do and why we exist; it's vital that we listen to them and support them to feel confident and recognised in their extremely valuable role. Our Dementia Carers Centre will cement everything together, as a unique place where carers can drop their shoulders and relax whilst learning and re-charging their batteries.'*

The new name was launched in Birmingham by a group of carers attending the most recent DCC course: Eirwen Greves from Sutton Coldfield assisted with the celebratory cake cutting and Kush Parmar from Birmingham with the ribbon cutting to unveil the new logo.

DCC is also creating a specialist research unit to investigate family carers' needs, experiences and desired outcomes. In turn, this research will support campaigns to influence policy and raise public awareness about family carers of people with dementia.