

Dementia Newsletter

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

Guest Letter

It is a privilege and honour to be offered the opportunity to write this six-monthly letter which usually comes from the Revd Dr Margaret Goodall.

I have been reading the Newsletter since 2015 and involved with the executive committee of Christians on Ageing for the past year. This is an organisation with huge potential which, in recent years, has not been fully realised. Older people are increasingly important in a country which currently struggles to like itself and individuals search to find a meaning and philosophy for life. We carry the experience and, perhaps, the wisdom of years. We are fitter than were previous generations. We are not as poor as they, and there is a wealth of resources which we can access for education, pleasure and service. Add these benefits to the network of churches throughout the nation and you see that we are equipped to make a difference. Christians on Ageing website has been improved and set up to encourage interaction and up to date comment.

There is no doubt that churches all around the country have begun to identify and address the needs of people with dementia more positively: church premises are used for drop-ins, cafés, singing and other activities. These are usually available to people of all faiths or none. The presence of individuals disabled by dementia or other conditions, does not ban them from remaining involved in church life – in worship and in helping in a service capacity. Where there might have been ignorance and fear, there is now much more understanding. Dementia and disability present challenges which draw us together to help and to overcome adversity.

Notable in the research field is a shift to acknowledge that prevention, though not possible in an absolute sense, is very much our most effective strategy: improvements in general health and welfare are associated with improved life expectation, but also with a reduced incidence of dementia. This has been demonstrated in the UK, in the USA and in Australia. The evidence comes, not from controlled double-blind trials, but from observations of the experience of cohorts of people living within the culture and economy of the country and the time. The reduced incidence is not shared in communities where people lack work and adequate finance.

Sadly we are learning that life expectation in this country has begun to fall during these years of austerity, especially amongst women: the gap between rich and poor has widened. It seems that these findings are not stimulating political initiatives

which might close the gap and thereby reduce the incidence of dementia and return life expectation to the year on year rises which we had come to expect.

Excitement raised by the Royal College of Physicians' altered position on the issue of assisted dying or euthanasia has released furious debate. It is clear that the majority of physicians and almost all those practising in Palliative Care find no favour for a change of law. Yet passionate, if not truly well-informed experts and celebrities, vent anger at their imagined prospect of possible unmitigated suffering from cancer or dementia and shout for the right to shorten life – or have it shortened for them. Not very veiled is the hint that people with such conditions be encouraged to free others from responsibility to care for them. Valuing people in all their conditions is an ethos to be held dear, and held on to unerringly.

David Jolley FRCPsych
Altrincham and Bowdon Vale

News

The October 2018 issue of the on-line Journal of Wesley House Cambridge contains an article by Janet Morley, 'Guarding the "holy fire": dementia and the mystery of love' (vol 4 issue 1, pp77-93), a transcript of the annual Joseph Winter lecture, delivered in July 2017 to the churches in Wakefield. It is a theological and practical reflection on her experience of caring successively for her mother, aunt and father who all developed dementia in later life. The following is the abstract: *This article looks at how the 'holy fire', or spirituality, of a person can be protected as part of the dignity of a person living with dementia. Dementia sufferers can often be portrayed as less than fully human, but this 'normal practice' ought to be challenged. The neurological explanation for dementia does not tell the whole story, and a more person-centred approach seeks to remember the longer narrative of a person's life to understand ongoing communication and to affirm the continuing personhood of the dementia sufferer. Awareness of spirituality is crucial to this approach, and Wesley's line, 'my acts of faith and love repeat' {from his hymn 'O thou who camest from above'}, gives some framework to how this might be developed.*

On 24 October the Guardian featured 'Connie's Colander', the latest production by the Oxford-based Human Story Theatre, written by Gaye Poole, an actor and former psychiatric nurse based upon her experiences of doing reminiscence drama in nursing homes and day centres. Funded by Arts Council England the presentation

has been made to audiences of 35 in 18 libraries across the south-east, and now more than 75 libraries, community venues and hospitals to date are in process of making future bookings. The show is followed by a Q&A with a medical dementia expert and has helped people with Alzheimer's and their family carers feel less alone.

On November 8 at the Hilton Brighton Metropole, Carrie Twist was presented with the award of Dementia Care Champion 2018 for her work as Stories for the Soul co-lead and Playlist for Life Trainer. Carrie is a valued member of CCOA's executive committee and we extend to her our sincere congratulations

On 13 November the BBC Today Programme announced that research at University College London had discovered how to identify those at risk of dementia before the symptoms appear. The study followed some 3,000 middle-aged persons over a period of 10-15 years after ultrasound scanners had been used on their necks to measure the pulse intensity, finding that those with the most intense suffered more subsequent cognitive decline than the others. The study lead, cardiology Professor John Deanfield, explained that it has long been known that the flow of blood through the carotid arteries affects the brain. He advised that 'what's good for the heart is good for the brain' and that our lifestyle can be modified through diet and exercise to help lower blood pressure. Early identification of the risk of cognitive deficits including dementia can lead the way to earlier treatment.

However, information was released on December 31 indicating that although a free national health check is offered to people aged 40-74, less than half have availed themselves of the opportunity in the past five years. The twenty minute painless assessment screens for heart problems, kidney disease and type 2 diabetes, all of which have been associated with an increased risk of developing Alzheimer's disease and/or vascular dementia.

Since 1986 research has suggested a possible relationship between macular degeneration and Alzheimer's disease since both are believed to be caused by the build-up of [amyloid-beta](#). In Alzheimer's disease, amyloid-beta plaques accumulate in the brain, while in macular degeneration amyloid-beta forms fatty deposits behind the retina called drusen. Plaques and drusen appear to have [similar composition](#) of proteins and fats, and utilize the same mechanisms to damage surrounding tissue. An article by Laird Harrison in the Journal of Ophthalmic Research in July 2018 reinforces this proposition which can be regarded as having great potential since eye imaging is so much simpler and cheaper than brain scanning.

In mid-December it was suggested that surgical instruments used in brain surgery should be carefully treated to ensure that they are not contaminated with proteins linked to Alzheimer's disease. Professor John Collinge, director of the Medical Research Council prion unit at University College London said that although Alzheimer's disease is not contagious, there was a slim risk that harmful proteins that drive the disease could spread through brain surgery and other rare procedures.

Just before Christmas, as a consequence of a new piece of work led by a group at Newcastle University new guidelines were issued to address the thorny question concerning the suitability of people with dementia to continue driving. It is entitled ['Driving with dementia or mild cognitive impairment: Consensus Guidelines for Clinicians'](#).

Yorkshire and Humber Dementia Action Alliance, working in conjunction with the Stephen Joseph Theatre in Hull, has run a term of dementia-friendly music and movement for people living with dementia, their families and friends in the theatre and reports an encouraging response. It is hoped that this work will continue.

In January the journal Neurology contained a report of a study, carried out by a team led by Dr Aron Buchman of Rush University, Illinois, of 454 individuals, 191 of whom had dementia, as they progressed through older age to death which on average occurred around the age of 91. The study appeared to show that those who clocked up higher levels of physical activity fared better when it came to cognitive tasks. Better motor abilities seemed to offer some cognitive protection.

In mid-February the Centre for Addiction and Mental Health in Toronto reported the success of an experimental drug that has been shown to rapidly bolster ailing brain cells in mice. If this is replicated in human trials there is hope that by targeting and rejuvenating specific cells in the hippocampus it could reverse memory loss and mental impairment in people with depression, schizophrenia and Alzheimer's disease.

A report published in early March by the Global Council on Brain Health and launched in this country by Age UK suggests that feeling good and being emotionally well is linked with better brain health among the over-50s. Visiting loved ones, getting out in the community, volunteering, staying active and getting a good night's sleep are all recommended to boost emotional wellbeing. Director of Age UK Caroline Abrahams also suggests that such measures may help to reduce the risk of developing some forms of dementia.

On 26 March the media highlighted Spanish research published in the journal Nature Medicine showing that, contrary to earlier views, human brains can produce fresh brain cells until people are well into their 90s. However, such production was seen to fall in those with Alzheimer's, even amongst those in whom the disease had only recently taken hold. The results were based upon analysis of brain tissue donated by 13 healthy individuals aged 43 to 87 and 45 dementia patients aged 52 to 97. Lead scientist Maria Llorens-Martin suggests that further research is required in an endeavour to discover what 'independent mechanism, different from physiological ageing, might drive this decreasing number of new neurons' in the case of those with dementia.

On March 28 Guardian 2 published journalist Anne Penketh's short article entitled 'My mother has Alzheimer's. She deserves better than this'. Member of Christian Council on Ageing's executive committee, John Lansley writes: 'Anne Pesketh describes how her mother, who is in her 90s, and has been living in a care home has now developed aggressive paranoid behaviour which the home cannot deal with, and she has had to move to a specialised (and more expensive) home. The story of the pressure on the family carers is sad and familiar, but right at the end Penketh finds 'a crumb of comfort': 'A staff member at the new home looked up after writing [my mother's name]. "One of my teachers was a Mrs Penketh" she said, "I wonder if it's the same person?" It turns out that Mum taught her how to darn socks in needlework. "It would be ace if she comes here", she said. I had to fight back my tears.'

And so did I: I found it immensely cheering.'

The April issue of the journal Nature Neuroscience contained a report of a Boston-based study of working memory (which holds information for short periods of time) in which 42 people aged 20-29 and 42 aged 60-76 were assessed, showing that the latter group were slower and less accurate. When all participants were subject to 25 minutes of non-invasive electrical pulses the memory of the older adults (especially the worst subjects) improved for 50 minutes to match the performance of the younger group. This may prove helpful for those with dementia though the findings will need replicating by much larger clinical studies and in any case may not apply to those with longer-term memory loss.

Reviews

Christine Bryden, 'Will I Still Be Me? Finding a continuing sense of self in the lived experience of dementia', Jessica Kingsley Publishers, 2018, 142pp, £12.99, ISBN 978 1 78592 555 9

Recent years happily have seen the publication of increasing numbers of books by authors who are themselves living with dementia and thus who write from the 'inside' rather than from the 'outside' of that experience. The pioneer and most prolific of these authors is Christine Bryden whose current book marks the apex of her corpus to date. Its provocative title continues the series that contains 'Dancing with Dementia' and 'Who will I be when I die?'

Diagnosed with dementia 24 years ago, Bryden continues to challenge the prevailing negativity which sees dementia as a story of inevitable loss of faculties and ultimately of self and thus to encourage those with dementia and their carers. She argues cogently that three aspects of 'our sense of self' continue throughout the lived experience of dementia. Those with the condition continue to be an embodied self, able to distinguish self from non-self; their relational self with others (and the divine) continues to be all-important; and their narrative self is derived from finding continuing meaning in life in the present moment, even when the past becomes blurred and the future beyond comprehension. Her ultimate aim is to emphasise what remains in dementia and to encourage a truly diverse society to include those with dementia as equals.

In just 130 pages of text, Bryden examines each of these propositions at greater depth, making copious references both to her earlier works and to researchers such as Steven Sabat, Susan McFadden, John Swinton, and Elizabeth MacKinlay with whom she has worked for many years - whilst also facing up to the more negative views of other writers. She also includes numerous brief anonymous case studies deriving from a variety of ethnicities and religious persuasions.

It has to be said that the chapters are somewhat overlapping, repetitive and at times dense so I will simply cherry-pick some of the things that have struck me most:

- Bryden comments that, although her dementia makes the process of writing and analysis more difficult, it does also make it more authentic. (And after all, she has recently completed her PhD!)
- She recognises how damaging was her diagnosis, dominated by the biomedical understanding of dementia, leading to the suggestion that she should in effect retire at the age of 46 and prepare for the worst. How fortunate that she found

such fertile new channels of work, demonstrating that she is 'far more than a deteriorating self in an increasingly empty shell of a body'!

- 'Dementia is accompanied by stigma' because 'society values competence, intelligence and autonomy, and devalues those of us who might be unable to demonstrate these attributes'.
- Belonging to a supportive faith community helped her to discover 'a new sense of an emotional and spiritual self'.
- Memory loss is almost invariably associated with dementia. Bryden prefers to call it 'recall dysfunction' and affirms the need for 'additional prompts' to recall memories e.g. help from other people and, in her case, the installation of a personal calendar application on her phone, tablet and computer; further suggesting that some neural pathways may survive into advanced dementia - hence the 'lucid episodes' sometimes noted by those she calls 'carepartners'.
- 'The most important relationships for a continuing sense of self {and of meaning} can be religion, nature, art or even our grandchildren.'

Does Bryden succeed in her contention that dementia cannot eliminate the self in the person living with the condition? Certainly partially. She clearly demonstrates that the self surely remains for a very long time, especially if the care received is always offered in that strong belief. It can probably never be proven whether it remains true even in the very last stages of the disease but belief that it does is surely a far better option than prematurely writing off those with dementia as non-persons.

Bryden's final words are 'I'm still here!' As someone unable now to engage in research because of a growing awareness of an increasing loss of words and analytical abilities, I have to say that I am much encouraged. Deo gratias.

Albert Jewell

Jackie Pool, 'Reducing the symptoms of Alzheimer's disease and other dementias: a guide to personal cognitive rehabilitation techniques', Jessica Kingsley

Publications, 2019, 176pp, £14.99, ISBN 978 1 78450 5 Jacky Pool is a well-known and respected worker in the dementia care community of the UK. The back cover of this book reminds us that she was crowned 'Best Dementia Care Personality' 2011. This is Jackie summarising her experience and current beliefs and practice after 40 years: 'I don't want my learning to go to waste'. She shares personal information about her family and about her career, including encounters and conversations with other leaders in the field. Her style is modestly conversational and will be received as down to earth and trustworthy by families eager to be informed and given guidance,

and by professionals filtering the plethora of views which enrich but confuse the field.

Her mission is to address and reverse the cognitive loss which is core to the dementias. She cites collaboration with Professor Tom Kitwood and their coinage of the word 'rementia'. There are reviews of current understanding of the biochemistry and neuropathology of Alzheimer's disease and an admirable emphasis on how diet and life-style influence the genesis of dementia and its progress once established. She slants her rehabilitative programmes to improve cognition, 'Cognitive Rehabilitation', and recommends the use of her structured planning and monitoring approach, the Pool Activity Level (PAL) instrument. There is reference to her involvement in recent evaluations of Cognitive Stimulation Therapy and Cognitive Rehabilitation with details and examples of the techniques employed. There is much to be said for these innovative therapies. Their benefits include improved physical and mental health and much-needed guidance for families and professional carers. Improvement in cognitive performance may be the hardest measure to achieve and appreciate, but the wider benefits are sound and worthwhile.

Surprisingly there is little said about the power of music. There is little mention of spirituality, reflection, faith or prayer, which is a shame, given the objective of demonstrating the value of all dimensions of every person.

This is not an academic thesis, but it is a valuable review of matters as seen by an experienced, well-informed and committed practitioner and will be welcomed as such.

David Jolley

Lavinia Greenlaw, 'The Built Moment', Faber and Faber 2019, £14.95 The first part of this collection of poetry describes the observations and feelings of a daughter whose father is developing dementia. In a series of 24 short poems she tries to imagine what it is like for him to live entirely in the present, with no memory of the past or sense of the future: who is he, when he doesn't know who he was? In one particularly poignant poem she describes rushing late to see him, only to realise that he had had no expectation of her coming, or that when she leaves he will have no memory of her visit. So how can she share her love with him? "The late soft colours of his returning to me are already gone."

These are inevitably sad poems, but deeply sensitive to both father's and daughter's dilemmas. The images of loss and confusion encourage the reader to explore and

reflect on this most difficult of relationships, and can be returned to again and again in a setting where imagination has more to offer than medicine. Well worth reading.

John Lansley

(The above review also appears in the Summer issue of Plus, the quarterly magazine of Christian Council on Ageing. Ed)

Networking

Faith in Older People

Out of their extensive experience Edinburgh-based Faith in Older People have produced a learning resource for churches and other faith communities 'to develop more support for people with dementia and their families'. Its twenty pages comprise a helpful introduction which offers a six-question quiz on how dementia-friendly your community is and a section on learning about dementia, followed by five suggested 'actions for change' comprising:

- **People.** How to improve communication.
- **Places.** How to improve the physical environment.
- **Resources.** Focusing on the services and facilities available for people with dementia.
- **Community.** Collaborating and planning across the whole community.
- **Pastoral visiting.** How to be with a person with dementia in a relaxed and positive way.

Importantly, all these sections lead to an appropriate action plan: What actions will we take? Who will do what? When will we review our progress? Finally, there are helpful appendices on available resources and books. Maureen O'Neill and her team are to be congratulated on producing this resource which is freely available to download from their website: www.faithinolderpeople.org.uk

Arts for Dementia

Secretary of State for Health and Social Care, Rt. Hon. Matt Hancock, at the World Dementia Summit and Social Prescribing Conference, stated: 'Access to the arts and social activities improves people's mental and physical health. It makes us happier and healthier.'

Arts 4 Dementia is a London based charity which offers stimulating arts programmes for people in the early stages of dementia and their care givers. Their website provides the only national listing of arts events for people living with dementia and

they train arts facilitators from around the country in early stage dementia awareness.

If you run a dementia-friendly event or are a dementia-friendly venue then they would love to help you promote your event/venue via their website. Visit www.arts4dementia.org.uk and click on 'Post an event'.

The therapeutic value of music

Research published last year by the International Longevity Centre UK (ILC) and the Utley Foundation found that music has significant physical and mental health benefits for those with dementia and helps them retain their speech and language skills longer.

On 9 January Ann Robinson wrote a trenchant report in The Guardian regarding the value of music therapy in the care of people with dementia, citing the case of Eileen Pegg who developed dementia in 2015 and became very anxious and agitated. Her carers at [Weston and Queensway care home](#) in Stafford were determined to find a way to make her happier, so they decided to see if music would help.

The care home, which is a specialist dementia care unit run by Methodist Homes (MHA Care Group), has provided music therapy for more than 10 years, and these sessions have made a real difference to Pegg. Now 91, she attended her first music therapy session in 2016, and was distressed but, according to care assistant Chloe Pugh, afterwards was 'a completely different person', smiling and recalling dancing with her husband. Pugh admitted, "We can't eliminate her anxiety completely, but we can help to alleviate the symptoms for Eileen, and help her engage more with what's happening around her". Singing and clapping along to music or playing instruments at her weekly one-to-one classes has helped Pegg become calmer, which has encouraged her to participate in other activities, thereby improving her appetite and mood.

She is not the only one to benefit from these sessions. More than 2,000 residents in MHA's 84 care homes take part in regular music therapy groups. Moreover, 'non clinical' activities such as singing hymns in worship, choirs, music groups and specialist apps are all beneficial.

Robinson points out that music uses different parts of the brain from language and so can be used to communicate with people with dementia, even if they no longer speak or seem to understand other people's words. As a result, it can help them

express feelings and ideas and interact with others, also reducing social isolation and encouraging more physical activity through dancing or moving to the music. Confirmation comes from Sally Greengross, International Longevity Centre's chief executive: "Analysis showed that music helps to significantly minimise some of the symptoms of dementia, such as agitation, and can help to tackle anxiety and depression".

The NHS long-term plan, published at the beginning of the year, promised to roll out social prescribing, including music and the arts, with the aim that by 2021 900,000 people would be able to be referred to social prescribing schemes by then, link workers connecting patients to local groups and support services. Matt Hancock says that this should reduce the need for the use of medication and restraints and that he fully supports work that "helps us move to more person-centred care – a key part of the NHS's long-term plan."

However, Robinson points out that this will come at a price, The King's Fund pointing out that social prescribing can be more expensive to commission than seeing a GP in the short term. On average, it costs MHA £30 per person for each music therapy session in its care homes. With social care finances stretched to the limit, music is not a priority in many care homes and the availability of community-based choirs and interactive music groups for dementia patients is limited.

Robinson highlights the recent launch of the Music for Dementia 2020 campaign which is backed by £1m from the Utley Foundation, with additional ongoing annual funding of £500,000. This we shall hope to feature in a future Dementia Newsletter.

Becky Allright: Dementia and Mission

I'm thrilled to be asked to write an article on the work I've been doing around dementia. I am a newly ordained pioneer curate in Drax near Selby. Before becoming a priest I worked for 12 years in health and social care in dementia care. I trained as a social worker, and then worked in project management and commissioning in Bradford and York. In that time I met lots of inspirational people who are 100% committed to improving services for people with dementia and their families. So in the church I've been helping to run dementia friendly worship sessions as fresh expressions of the gospel, that build a new worshipping community. This has been really good fun and challenging in many ways, but very rewarding to feel the spirit of the Lord moving among us as we worship together.

So the things I'd like to share are mainly about being a community. We all know that singing and music are great ways for people with dementia to reconnect with long-cherished memories. We all love the fellowship of church, and the welcome we receive. By putting these things together, and providing a safe space in church, families supporting someone with dementia, can relax into enjoying familiar hymns and songs, as well as asking for prayer and even sharing communion in a relaxed and understated service.

Like a good family service dementia friendly worship needs to have a still point when we can bring ourselves into 'holy ground' but also needs to be able to reach people without words. Like toddlers people with dementia respond to the welcome they receive, the opportunity to light candles or hang a prayer on a tree as much as they do listening to a talk or reading. I tend to use the Easy Read bible as it's simpler than many other translations however the Message is also a great way to bring words to life.

Not everyone with dementia is a regular church-goer but many families will seek out support at this time who wouldn't always want to be associated with church so it's not safe to assume that everyone will know the Book of Common Prayer or traditional liturgy. Some will and some won't. Like providing a service in a care home, it needs to be fairly ecumenically minded, as we may be worshipping together with Roman Catholics, Baptists and Methodists as well as Anglicans.

Dementia friendly worship is an amazing opportunity for people to be held and supported by the church in their time of need. Sometimes former churchgoers may stop coming, perhaps embarrassed to come anymore, or for many preachers and lay readers, not being asked to help anymore as their difficulties have made it awkward for everyone. In a dementia friendly environment, people who have lost confidence through frailty can also be included and involved in planning or delivering a talk. This can also lead to the wider family coming to support. One week in the church where I helped set this up in York, a grandson came to play music, and grandad was leading, so the whole family came to join in. None of whom were 'church' people.

Now I'm in a new context I'm supporting a quarterly service at Selby Abbey where we fundraise for Dementia Forward a local charity. For our next service we are planning to a healing theme and opportunity for anointing and prayer. If anyone would like to find out more, please do get in touch. rev.becky.allright@gmail.com

(My first contact with Becky came as a consequence of the launch last May of Livability's My Faith Matters which provides resources on spirituality for persons with dementia which can be accessed on:

<https://www.livability.org.uk/resources/my-faith-matters/>. Ed)