

# Dementia Newsletter

**No.49 May 2017**

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This newsletter is produced twice yearly by the Dementia Group of the Christian Council on Ageing, registered charity number 289463.  
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It is available free by email attachment or hard copy at £5 per annum

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

## Chair's Letter

Dear Readers

As some of you may know I retired from full-time work last October and have since been learning what it means not to have the day dictated by a diary – even if the diary was organised by myself! If I was to retire again there would be things that I would do differently... one being not to jump into other things, but to give space to see what came to the surface. That being said I have since the New Year spent time going through papers and journals about dementia collected over more than 25 years. They were kept – just in case they might be useful. But many were archived in the days before the internet was the first point of reference. Today I typed 'dementia' into the search engine and was blown away by the volume of material available. Where to start?!

I feel that the abundance of material available makes the task of this publication even more important as contacts, information, new research and book reviews are signposted to make the data more readily accessible.

I was contacted recently by a church that was trying to put together an informal group to offer support to carers and fun for those living with dementia. The first thing I suggested was to contact the editor of this newsletter for a copy. That would give up to date information and a feel for where support for churches can be found.

Much on the internet is very good but the amount of information can be daunting to someone looking for help. Perhaps we could forward the message with newsletter attachment to one other person and ask if they would like to receive it themselves. If you already do this, then thank you. If you don't then please, if you think the publication worthwhile – pass it on!

With best wishes

Margaret

## News

In early November the results were published in *Translational Medicine* of a trial of 32 patients with early stage Alzheimer's disease who had been given the drug verubecestat, which is produced by US pharmaceutical firm Merck, over seven days, healthy volunteers being also given the drug for up to two weeks. Samples taken from the fluid surrounding the brain showed that the drug had reduced the levels of two compounds which are known to be building blocks for abnormal amyloid proteins that lead to the plaques seen in the brains of Alzheimer's patients, thus slowing the pace of mental decline. Lasting benefits and risks need still to be assessed and during 2017 Merck is to run two phase three trials of 1,500 patients with mild to moderate Alzheimer's and 2,000 in the earliest stage. In August Biogen reported that their drug appeared to sweep away the abnormal proteins after they had appeared, whereas the Merck treatment seems to halt their production: switching off the tap rather than mopping up the water, as their spokesman Ian McConnell puts it.

The Office for National Statistics reported in early November that Alzheimer's disease and other dementias have replaced ischemic heart disease as the leading cause of death in England and Wales for the first time: 61,686 (11,6%) of 529,655 deaths were attributable to dementia (more than double than was the case in 2010). Increased longevity and earlier diagnosis may partly account for this.

On 17 November it was reported following collaboration between Alzheimer's Research UK, Deutsche Telekom and game designers Glitchers that the mobile phone game *Sea Hero Quest*, which tests spatial navigation skills, has generated a huge amount of data that could be developed into an early diagnostic test for dementia. The game has already shown that those aged 19 were 74% likely to hit a target compared with 46% among 75-year-olds, which contradicts previous studies suggesting that cognitive abilities do not decline later in life.

On the same day BBC Radio 4's *Today* programme featured the claim by Age UK and the Alzheimer's Society (backed up by

BBC's own findings) criticising the way older people are cared for in England as shameful and scandalous. The evidence is that there is an estimated 1.2 million over-65s going without the help they need, councils agreeing to support less than half those who approached them. Where home care was provided, serious problems were identified in the way dementia patients were treated, staff saying that they had not been given enough training to cope with the complex needs such people presented. Families reported such examples as loved ones not being given medication, being left in dirty clothes for days and going missing after homes had not been properly secured. Ministers insisted that plans were in place to support the care market. The next day The Guardian ran an account of a care worker who has a 12-hour day requiring some 23 house calls earning a total of just under £65 before tax. Such home calls, which are common in the care sector, are necessarily quite brief and place undue pressure on the worker trying to get from one place to another and give quality time to the client.

On 19 November The Guardian published a review by Sarah Boseley of the present position regarding drug research and use, stressing the fact that Lilly's recently-trialled solanezumab and Biogen's aducanumab have appeared to show effectiveness only for those in the early stages of dementia, the benefits of Aricept and similar drugs over a limited period, and the inappropriate use of antipsychotics in treating those with dementia. 'Sadly, there still seems little hope for those who already have moderate to severe dementia, beyond care and compassion.' Significantly, less than a week later it was announced by Lilly that results based on 2,000 patients with mild dementia showed no significant benefits. This has led to questions as to whether pharmaceutical companies are on the right track in targeting amyloid plaques.

In mid-December the British press (Telegraph, Mail, Mirror) headlined the outcome of a study at The University of South California of 400,000 people who took statins (prescribed to lower cholesterol levels) which appeared to show that the risk of developing Alzheimer's in regular takers was reduced by 12% in men and 15%

in women (though apparently not in black men). It suggests that this may be because of the effect of the drug on beta amyloids or by the drug's anti-inflammatory properties. Similar smaller-scale studies have shown mixed results.

The BBC Today programme on 14 December contained a report on progress towards the establishment of the Dementia Research Institute first announced by PM David Cameron in November 2015. The hub is located at the Institute of Neurology at University College London and is linked with regional centres so that work can be co-ordinated. Its aims are to better understand the disease and its treatment and to oversee research and the support of people with dementia and their families. It is suggested that dementia should be seen within the wider sphere of neurological diseases such as Parkinson's.

Actress Carey Mulligan was one of the guest editors of the Today programme in the week after Christmas. She drew special attention to the needs of carers for people with dementia citing her own experience and arranging Michael Palin to be interviewed

concerning the dementia of fellow-Monty Python actor Terry Jones. This stimulated much discussion which drew attention to the growing sense of isolation for such carers and the sometimes insensitivity of medical services to their situation when 'you can't be ill yourself'.

On 29 December the Today programme and some newspapers featured a report of research by Alex Forsythe of Liverpool University who analysed over 2000 paintings by seven famous artists which appeared to show that changes in the brush strokes (notably of Willem de Kooning and James Brooks) gave the first hints of cognitive decline many years before dementia is diagnosed.

Front page headlines in the Daily Mail and Express newspapers on 5 January placarded the outcome of a study published in the Lancet which found that people within 50-200 metres of major road arteries were up to 12% more likely to be diagnosed with dementia, amounting to a small but significant increased risk. The eleven-year Canadian study which tracked 6.6m people showed no such connection with either Parkinson's disease or multiple

sclerosis. A relationship with either or both noise and air pollution are possible causes but other as yet unrelated factors may be involved and further research is required before firm conclusions can be drawn.

In early January PubMed.gov, the US National Library of Medicine, reported that research at Kyushu University in Japan, showed that if the DNA lesion 8-oxoguanine (8-oxoG) is highly accumulated in the brain it can lead to vicious cycles of oxidative damage, which may then trigger the neurodegenerative process seen in Alzheimer-type dementia.

On Sunday 8 January, the BBC1 Countryside programme spent some time drawing attention to the added problems for families in the country, especially farmers, coping with older family members with dementia, especially the risks attached to using heavy machinery and the need to travel to access support services. The work of the rural dementia task force, some parishes in rural areas and dementia-friendly churches was featured and the urgent need for national coverage urged. A report is being prepared by Plymouth University.

Sir Terry Pratchett's unfinished autobiography formed the basis of a BBC2 docudrama broadcast on 11 February. Diagnosed with Alzheimer's in 2007 he subsequently completed seven novels with the help of his assistant Rob Wilkins before his death in 2015. Wilkins recalls how early on Pratchett accused him of losing the 's' on his keyboard and in late 2014 suddenly said 'Terry Pratchett is dead'. Pratchett likened his experience to walking in a park where the scenery bewilderingly kept changing.

The findings of a study of the post-mortems of six footballers who developed dementia after long careers in the sport, published in February in the journal *Acta Neuropathologica* showed that all six had Alzheimer's and four also had chronic traumatic encephalopathy (CTE), a degenerative disease linked to repeated blows on the head. However, the study is very small-scale and cannot show whether they would have developed dementia even if they had not been footballers.

On 21 February *The Guardian* reported on an address at the American Association for the

Advancement of Science in Boston by Janet Cohen Sherman, clinical director of the psychology assessment centre at Massachusetts general hospital, concerning new findings revealing distinctive language deficits in people with mild cognitive impairment which may be a precursor to dementia. This showed itself in a tendency to ramble and to suffer mental block in dealing with ambiguous pronouns. Such a decline is shown to be evident in the later writings of such authors as Iris Murdoch and Agatha Christie, as well as in the later speeches of Ronald Regan.

In late February BBC Wales TV broadcast a sensitive and insightful hour-long programme on dementia, 'Beti and David – Lost for Words'. Narrated largely by Beti it charted the decline in her husband of over 40 years, the challenges she had to deal with (such as toileting, showering and mood changes) and the rather disparate services available in Cardiff. She pointed to the need for a one-step service which would offer support and access to needed services. She also shared her experience with medical students in training. She went to Scotland where she found the

NHS offers an 'informed link' to every carer when dementia has been diagnosed. Beti declared that those unable to speak for themselves needed advocates and she herself certainly appears to be a most articulate and effective one.

In late March Rahul Desikan of the University of California announced that the polygenic hazard score test used with more than 70,000 people has shown that it could accurately predict an individual's risk of developing Alzheimer's: those in the top 10% would do so at an average age of 84 compared with 9% for those ranked in the lowest 10%. Alzheimer's Society's James Pickett cautioned that further testing is required.

In his 'A Point of View' on BBC Radio 4 on 2 April Tom Shakespeare argued cogently for giving some priority to treating dementia as a disability rather than simply a disease (or diseases), otherwise it is hard to press for the human rights of those with dementia which are so often overlooked. He suggested that even the emphasis on becoming more 'dementia friendly' can be seen as rather patronising, preferring using the word 'enabling'.

In April the journal Nature reported research at Stanford University which has shown that infusions of protein found in human umbilical cord blood had reversed memory and learning problems in aged mice by revitalising the hippocampus. However, what works in mice very rarely appears to do so in humans. The next day media reports appeared of a study showing that antidepressants could benefit those with some forms of dementia,

On April 20 it was announced that Cardiff has been chosen as the location for the UK's biggest dementia research centre established by the Dementia Research Institute. A grant of £13m has been awarded, with a potential for a further £17m over the next five years, allowing for the employment of 60 researchers. Professor Julie Williams, who is currently the Chief Scientific Advisor to the Welsh Government and Professor of Neuro-psychological Genetics at Cardiff University, will lead the new centre.

On April 21 somewhat sensationalist press reports suggested that drinking a daily can of artificially sweetened diet soft

drink could be associated with a much increased risk of both stroke and dementia, although no causal connection has been established.

## **Book Review**

**'Dementia: Hope on a difficult journey' by Dr Adrian Treloar (2016, Redemptorist Publications, £9.95, ISBN 9780852314715)**

One November evening some years ago my 93-year old father fell in his bedroom, fracturing his hip and collar bone. Excellent emergency care ensured that a week later, sitting up in hospital, he welcomed my daily visit and the local evening paper. He was less pleased however when he spotted the paper's date, asking why I had brought a November newspaper when we were now in February...

It was my first indication that the dementia which his mother had experienced was now manifesting itself in the son, possibly exacerbated by the recent anaesthetics. What I would have appreciated at that time was a copy of Adrian Treloar's recent book *Dementia: Hope on a difficult journey*.

Dr Treloar is a consultant and senior lecturer in old-age

psychiatry who has been developing and running services for people at all stages and severities of dementia for over twenty years. He is also a Catholic, so this helpful book of 29 short chapters is divided into those which concentrate on Practical Care and those which are concerned with Spiritual Care. Both sections are clearly presented, with an attractive readable typeface, and unusual illustrations, both paintings and photographs (but with few credits).

The chapters on Practical Care cover issues which can be found in many other dementia-information publications, but are succinctly explained with headings such as: What is Dementia? Medical treatments; Planning and Thinking about the Future; Ways of Communicating; Memories; Preparing a Life Story Book; Palliative Care, and others. These are prefaced by an interesting introduction which raises questions about the pros and cons of longer life - whether the joys of living to see one's grandchildren grow up are offset by the illnesses which beset us in later years.

However, the most original chapters are those which

concentrate on Spiritual Care. Although Dr Treloar is a Catholic, he hopes that these will be of value to people of all faith backgrounds. This section of the book begins as follows:

'Dementia is often seen as a medical illness. But it is much more than that. Most of all, dementia is a social and spiritual illness; it is, for everyone, about a profound change in life and also part of a journey towards God. So if we neglect the spiritual dimension, then we fail our patients and loved ones' (p101).

The section is preceded by chapters on Sin, Despair, and Hope, topics not usually found in dementia manuals. These stress the importance of finding out about a person's faith background as early as possible, and suggest ways in which people can be supported in sustaining their lifelong beliefs. (Again I was reminded of my own experience with my father whose subsequent agitation could often be calmed by praying the rosary together in the evening, a custom he had learnt as a child in rural Ireland). Almost all faith traditions have prayers, hymns and customs which can be recognised by people with

dementia who have become familiar with these in earlier life; even the wearing of certain symbols, such as a crucifix, may be helpful. Treloar gives examples of Catholic sacramental practice and prayers, but whose example can be of value to others.

Towards the end of the book, Treloar has a chapter entitled 'Supporting the faith of earlier life - Not the time for conversion', whose title speaks for itself. Indeed, the whole book offers information for people of all religious faiths as well as for atheists, many of whom may have to go on this difficult journey at some time, and those may find themselves owing a debt of gratitude to Dr Treloar for his wise advice.

Anne Forbes

## **Networking**

### **The Cumbria project**

In May 2015 the Social Responsibility Forum of Churches Together in Cumbria (CTiC) made the bold decision that it would seek to 'make all churches in Cumbria dementia-friendly by 2020'. Two years on, I welcome the

opportunity to present a progress report.

CTiC asked me to take responsibility for the project as Dementia Coordinator. I have the support of a Dementia Reference Group; the members are drawn from six denominations, and also include the local volunteer representative of Alzheimer's Society in Cumbria. All of us have family experience of dementia or are professionally engaged with the needs of people affected by dementia. But central to the success of the project is the recruitment of a much larger group of volunteers, to act at local level, in respect of a single church or chapel or of a team or group or circuit.

We coined the term 'Dementia Enabler' for the local volunteers. That which is expected of a Dementia Enabler (DE) is that they:

- Should be, or become, a Dementia Friend and should encourage others to become Dementia Friends also;
- Should have a general awareness of the support services that are available in their local community for people affected by dementia.

- Should encourage the local church or group of churches to become dementia-friendly (in terms of welcome, worship and environment).

We were concerned to ensure that the DE should be supported by their local church, and we have therefore asked that the local church leadership should promise to support them, by prayer, by giving them regular opportunity to report to the church council or other body, by giving due consideration to their recommendations as to ways in which we may become dementia-friendly and by meeting any necessary expenses

The scene was thus set for the launch of the project in January 2016. I am glad to be able to report that, following two recruitment rounds – the second being at the start of 2017 – we now have 90 DEs drawn from across our vast county and from across the denominations (Church of England, Church of Scotland, the Baptist, Methodist, Roman Catholic and United Reformed Churches, the Salvation Army, the Society of Friends and a branch of the King's Church).

DEs are not left comfortless:

- We held a Workshop for them last year (in association with the Christian disability charity, Livability) and a further one is to be held this June.
- A 'Dementia Enablers' Handbook' has been produced. This includes contact details for local services provided by Age UK and Alzheimer's Society and of the memory services of the Cumbria Partnership NHS Trust.
- An e-newsletter is regularly issued to DEs.
- Local meetings of DEs are being piloted in Penrith and in South Lakeland.

Developments directly attributable to the project include the holding of a special service at Carlisle Cathedral in Dementia Awareness Week in 2016 (this will be repeated this year), and the introduction of a monthly service with the needs of people affected by dementia uppermost ('the Kendal Tea Service') at Kendal Parish Church. The tea service is set to be copied elsewhere in the county later this year.

To underscore the point that dementia is everybody's business'

not just that of the Reference Group and the Enablers, we held the first Cumbria Churches' Dementia Conference' last autumn, and 75 people attended. The second will be on Saturday 25 November 2017.

There is a long way to go, I will concede, but I am encouraged by the start that we have been able to make. No one else has ever attempted to make so many churches dementia-friendly across so wide an area in so short a time, and it is my prayer that He who has begun a good work in us will bring it to completion – and that the Cumbria project may commend itself elsewhere.

For more information, (or for an invitation to the Conference on November 25<sup>th</sup>) please contact David Richardson ([dardesk@aol.com](mailto:dardesk@aol.com), tel. 07917 668235)

*Note:* David is Reader and Churchwarden at Kendal Holy Trinity. He is also Chair of the Kendal Dementia Action Alliance and a Legacy Ambassador for Alzheimer's Society.

## **Dementia Conversations: a time and space for us (somewhere)**

Dementia is with us and is widespread. Greater survival into later life means that the number of people with dementia has increased and will continue to increase. The consequences of this for individuals, families and the wider community have been recognised. Huge efforts have been made since the launch of the government-initiated dementia strategy in this country in 2009 to help people be aware of the condition and to improve recognition, assessment and treatment of dementia and the care and support of people living with dementia and their families.

Notwithstanding this greater awareness, Revd Veronica Brown was moved by the panel discussion that followed a reading of the play, 'Don't Leave Me Now', written by Brian Daniels and performed at Quay Arts, Isle of Wight.

Those who had cared for family members with dementia had a deep need to talk about their experiences – not just of the impact of dementia on the lives of their loved one, but on their own

lives: the difficult decisions that family carers must make and the guilt that follows, the endless days and long nights of caring without reward and in complete uncertainty, their lives turned upside down with little relief in sight; limited medical guidance and the sheer loneliness of it all.

These people did not feel safe. They did not feel respected. Agencies presented a fine front, but behind this there was inadequate follow up, limited flexibility and failure to listen to people's personal, complex and changing needs. They were desperate for the opportunity to engage in honest and meaningful conversations which might contribute to their personal growth, and influence the support which they and other carers and people with dementia receive.

In collaboration with Barbara Stephens, Chief Executive of Dementia Pathfinders (<http://dementiopathfinders.org/>), Veronica determined to make these wishes come true. Dementia Pathfinders is a recently established social enterprise seeking to offer therapeutic care and support for people living with dementia and their families and to

provide education and learning for people working in the dementia care field. 'Dementia Conversations' has become one of the projects which Dementia Pathfinders is supporting.

At St James' Church in East Cowes 'Dementia Conversations' was launched in the autumn of 2015 and has continued monthly since then. It seeks to reach out to family carers, supporters and friends of people living with dementia and anyone with an interest in dementia who would like to learn more about the condition and the services available. Invitations were posted via Wight Churches, on the website Street Life, on posters and pew notices. The format offers a two-hour themed session each month, with a break for refreshments and informal discussions/networking.

David Jolley and Revd Ros Watson became aware of this initiative and have adopted the idea at Bowdon Vale Methodist Church (near Altrincham in South Trafford). Invitations are not restricted to church people. Bowdon's publicity has included the local free weekly paper, balloons and notices on the streets. Meetings are in the

afternoon and open to anyone with an interest in dementia: people with dementia are especially welcome.

Both initiatives are proving worthwhile. They attract about 20 people to each meeting. We are learning from each other and from invited experts on topics which are identified as needing better understanding. A great deal of love and mutual support is occurring between those who attend. We are beginning to identify activities which we can contribute to improve the spectrum of support and education for and about people with dementia locally. There are gaps in the systems provided by statutory and voluntary agencies. Maybe we can help by identifying them and working with primary health care, social care and specialist care to mobilise modest but tailored and responsive activities which fit our local needs – with best use of finances and other resources.

The most important strength will be the provision of a space and regular time for ongoing listening and reflection. People want to grow through their experience of dementia – be it as individuals with dementia, people caring for family

members or working as professionals, or people simply fascinated or concerned about the significance of dementia as a condition within humanity.

We hope that other churches and faith communities will consider providing time and space for 'Dementia Conversations'. If this grass-roots activity can catch fire across the country it might have great benefit for individuals and finesse the national response to the needs of people with dementia and their families to much better effect. If people want to know more or make comment or suggestions – please make contact via Dementia Pathfinders [info@dementiathfinders.org](mailto:info@dementiathfinders.org)

### **Godly Play - let the adults play!**

How can something that was developed for children – especially something with the word 'play' in it – be suitable for older people? Godly Play, which was founded by Jerome Berryman, is an approach that helps people to explore their faith through story and to enhance their spiritual experience through wonder and play. It is a well-established method of spiritual accompaniment that is based on research and practice in the fields

of education, psychology, theology and spirituality.

When I discovered Godly Play fourteen years ago my understanding of play dramatically changed and this has been life changing in terms of my own spiritual journey and how I view my role as an accompanier rather than as a teacher. I believe that story and play are essential for our well-being whatever age we are. Play enables us to enter into the creative process and where there is genuine play we are living in the present. People who train as Godly Play mentors for children find that Godly Play also 'works' for them as adults.

My church in Sheffield uses Godly Play with our children – but we also use it with people of different ages and needs and in many different contexts: children and staff in schools, adults who have mental health problems, people training for ministry, at a support group for international women, in adult fellowship groups, for intergenerational worship and in care homes for older people. Other churches in the area are also finding creative ways to use Godly Play, and Sheffield based 'Mutual Blessings' supports spiritually-

enriching practices using the method and principles of Godly Play with people of all ages or needs, but especially those who may be on the edge of the church's ministry.

Four years ago a couple from my church began offering Godly Play in two care settings for older people as an alternative to the traditional worship service. It was warmly welcomed by both the elders and the staff. We realised that adaptations to Berryman's method of accompaniment for children need to be made if we are to offer the best we can for older people. The spiritual needs of an older person are obviously different from that of a child and Godly Play can serve different purposes depending on the stage of a person's spiritual journey. For example, we are very intentional about Christian formation when working with children, whereas for people in their third and fourth age it is accompaniment as they make meaning out of their life's story that might be more important. In addition, the older person may have physical or cognitive needs which require adaptations of the story and other elements of the session.

Lois Howard in the USA has been using Godly Play for over ten years with a group of older people who have dementia and her work can be found on the website for the Godly Play Foundation. However, there is much work to be done regarding adaptations of the method for all the contexts in which Godly Play can be offered in care settings in the UK. Hence the Godly Play with Elders Project which Mutual Blessings started in January 2016. We are working collaboratively with practitioners and academics in relevant fields and are inviting everyone, nationally and internationally, to join our Godly Play Elders Team. There is an online space where people can share their stories and experiences, view resources, find all the latest updates on this work, ask questions and interact with other team members. You can find information and join the team by searching online 'Mutual Blessings Sheffield'

An important aspect of the project is the reflective evaluation carried out after the sessions, which includes inviting feedback from the older people and the care staff. This is a comment from one older person: 'If church had been like this when I was younger, I would

have stayed.' We want to create spaces that improve the well being of people – whatever their age. We realise that the name 'Godly Play' can create a barrier, especially because the word play is often misunderstood – and so in care settings we call it 'The Story Retold.' But – however we name it – let the adults play!

Kathryn Lord is an accredited trainer for Godly Play UK

For more information about Godly Play please visit [www.godlyplay.uk](http://www.godlyplay.uk)