



Dementia Newsletter

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

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Chairman's Letter

The 18 months of the Covid-19 Pandemic and recurrent lockdowns have been hard on people with dementia, their families, and the professionals caring for them, in England and Wales and throughout the world. Death rates amongst people with dementia have been amongst the highest, residents and staff in care homes and hospitals have been especially affected. Families and individuals have been kept apart 'for their own good and for the public health' – even to die without the



comfort of being together. There is sadness and there is rage. We now have admissions that mistakes were made in procedures which led to unnecessary suffering and an excess of deaths.

For a while the publicity and fear associated with Covid-19 displaced all concern for other health problems – but those problems, including dementia, have remained with us – to a degree less attended to, if not abandoned. Efforts are now being re-joined to catch up and get back on track.

Research has revealed that noise as well as pollution associated with inner city life makes it more likely that people will develop dementia. We have confirmation about co-morbidity between eye pathology and dementia. There is more and more detail about the risk of dementia and cognitive impairment developing in professional players of contact sports. It is not just football; it is not just heading. Longer involvement as a professional in any of these games increases the risk – but subtle impairment can be demonstrated within the first year. On the other hand, fears that HRT treatment leads women to a higher incidence of dementia have been found to be false. There may be other unwanted effects from such treatment, but dementia is not one of the outcomes to set against their benefits.

There have been no convincing advances toward a pharmacological treatment of Alzheimer's disease or any other dementia, but we do know more about approaches which reduce the incidence of the conditions and improve the quality of life for people and their families. There is a stronger understanding of the power of music and other art genres to lift the spirits and re-energise faltering mood and cognition. It is clear that these are the areas which will repay greater investment, as long as they are set in a context of fair and adequate provision for basic care and support of the population.

A first move has been made toward a review of Social Care funding for older people and this is particularly required for people with dementia who live with progressively increasing needs for care in the years before they die.

Death rates have increased in these months – life expectancy in England and Wales has fallen for the first time in decades. People have become more aware of death and occupied by a wish that painful and distressing symptoms be avoided or moderated as far as possible.

Some other countries have legislation which allows for assisted dying and there are calls for consideration of this as an option in this country. In association with the facility for Advance Directives this brings us to a new threat to the valuing of human life, especially of people who develop dementia.

Protection of the rights and interests of people with dementia has been brought to law out of conflict which has detained people in care homes and prohibited family visits for so long – and we are beginning to hear about the phenomenon of ‘predatory marriage’ whereby younger men take advantage of vulnerable older women who have lost capacity and seek to inherit their estate in the event of their death. We need to be aware.

David Jolley

News update

At the end of May, Robert Booth, Guardian social affairs correspondent, reported on trials underway at Lancashire teaching hospitals NHS trust in developing an algorithm which can curate music playlists appropriate to each individual, aimed at reducing suffering in Alzheimer's patients as well as stressed medical staff. This has led to reductions in heart rate of up to 22% as well as lowering agitation and distress in some cases. The algorithm allows the software to change forthcoming tracks if the original prescription doesn't appear to be working. The system is aware that music can be upsetting too, so there are 'red flag tracks' that are filtered out if the patient fears they may trigger upset by reminding them of a traumatic event.

On 11 June, Sky News were the first to announce that US regulators have approved the first new drug to treat Alzheimer's in more than a decade, possibly paving the way for it to be used in the UK. The Food and Drug Administration (FDA) in America somewhat controversially approved Biogen Inc's aducanumab drug (otherwise known as aduhelm) using its Accelerated Approval pathway, which is intended to provide earlier access to valuable therapies for patients with serious diseases.

The drug is unique in that it addresses the causes rather than the symptoms of Alzheimer's, targeting and cleaning amyloid plaque that builds up in the brains of those with the disease and can slow down and perhaps even reverse the damage in patients, especially those in the early stages of the disease. It has not yet effectively been tested in the case of those with more advanced dementia. The treatment could lead other pharmaceutical companies to create similar drugs and the UK regulator, the Medicines and Healthcare products Regulatory Agency (MHRA), to consider it for use in Britain. Sylvia Speight of Barnsley was diagnosed with Alzheimer's four years ago and told Sky News that it has 'changed my life'.

On 23 June it was announced that Cambridge neuroscientist Professor Giovanna Mallucci has been awarded the Potamkin Prize for Research in Pick's, Alzheimer's and Related Diseases, together with Professor Kenneth Kosik, from the University of California Neuroscience Research Institute, Santa Barbara. Professor Mallucci has been one of the leaders in the growing research area concerning the process that regulates proteins within the cell. She was the first to describe the role of PERK signalling over-activation in driving synapse loss and neuronal loss through repression of global protein synthesis rates.

Her work has shown how neuronal death can be prevented by blocking this process with drugs in mouse models of frontotemporal dementia and prion disease.

In mid-July the media reported that 25 observational studies suggest a likely association between high cholesterol levels in mid-life and an increased risk of developing dementia in later life. Alzheimer's Society agrees that one of the common genes that appears to increase the risk of late-onset Alzheimer's disease – APOE4 – plays a role in the processing and use of cholesterol and other fats in the brain but declares that more research is required. The Society also accepted that in the past there have been concerns that statins (widely taken to reduce the risk of heart attacks and strokes) might cause memory-loss and confusion but more recent studies have generally not found this link, indeed quite the reverse.

Over the last several years we have reported in this Newsletter on how the suspicion has grown of a likely association between long-term football playing and subsequent brain damage. On August 2 the Guardian reported that a field study, funded by the FA and the Professional Players' Union and led by Professor Willie Stewart of Glasgow University, as published in the journal JAMA Neurology, has demonstrated that it is players in field positions likely to head the ball frequently and over long years who are much more likely to develop dementia. This situation has pertained in the case of all 7,676 players surveyed who were born throughout the whole time period between 1900 and 1976. This has led the professor to raise the provocative question whether heading is absolutely necessary to the game of football.

On August 10, it was reported on BBC News and in the Guardian that it is possible for Artificial Intelligence to diagnose dementia immediately after a single brain scan of patients. It may also be able to predict whether the condition will remain stable for many years, deteriorate slowly or need immediate treatment. The algorithm is able to identify patterns in scans which even expert neurologists cannot see. Prof Zoe Kourtzi, of Cambridge University and a fellow of the national centre for AI and data science at The Alan Turing Institute has announced a forthcoming trial at Addenbrooke's Hospital and other memory clinics around the country to test whether it works in a clinical setting, alongside conventional ways of diagnosing dementia. In the first year, about 500 patients are expected to participate. Their results will go to their doctors, who can, if necessary, advise on the course of treatment.

In a study published in August in Molecular Psychiatry Cambridge and Leeds University scientists reported that they had successfully reversed age-related memory loss in mice which could lead to the development of treatments to prevent the same condition in people because the molecules in human beings are the same. The forgetful mice were treated with a virus capable of reconstituting the amount of chondroitin sulphates which control neuroplasticity.

In late August it was revealed that yet another outstanding footballer in his 80s, Jimmy Greaves, had died some years after developing Alzheimer's disease.

Also in August, the Guardian drew attention to the plight of the families of some late marriages of people with dementia. Joan Blass was 91 with severe dementia and terminal cancer. After her death in March 2016, her family found that a much younger man, age 68, had secretly married her five months previously. She never knew that she was married. Her family were shocked by how few checks there were to stop this marriage taking place. and believe that there needs to be better protection against such predatory marriage to prevent this happening to anyone else.

Book Reviews

In this Dementia Newsletter we are privileged to include reviews of three books written by authors who we can justly claim are part of our Christians on Ageing family.

Chronologically, the first of these, published in 2020 is by Robin Thomson who kindly sent us a copy of his book having been impressed by reading the May issue of this Newsletter.

The second, launched a few months ago in 2021, is by Michael Jackson, who was engaged with myself and a number of CoA members in several research-based articles sponsored by CoA and headed by Mike Lewis during the period of 2001-2011 on such diverse areas as coping in old age, moving into residential care and the role of the arts and hymns in the continuing wellbeing of older people.

Finally, I was fortunate to be sent an early copy of the now just published book by Tina English, a valued member of our present CoA executive committee, who brings to it all her considerable experience as director of the innovative Embracing Age organisation. I highly commend them all!

Albert Jewell

Tina English, 'A Great Place to Grow Old'

Darton Longman & Todd (2021) £9.99

In her explanatory preface, Tina makes clear her purpose in writing this book: that churches should become better equipped to re-imagine and fulfil their much-needed ministry to the growing number of older people both within their membership and in their local communities. By the time I finished reading it I felt that this purpose had been amply fulfilled. It is incredible how much she manages to include in a hundred pages comprising nine chapters plus four pages of Endnotes. Rich fare indeed!

Her first chapter sets the scene theologically, underlining how human beings throughout their lives remain dependent, made in the image of God who loves them, and relational creatures. Building upon this foundation, chapter two warns against churches rushing into premature action without first exploring who are the older people they have in mind and where they are to be found. This will involve careful looking and listening. The differences between the levels of care offered by sheltered housing, care and dementia homes etc are described. Some older people in their own homes may have minimal social contact, whereas others remain highly active but may be seeking outlets for their activity. Tina is clear that we cannot presume that we already know what these varied needs are, nor should we re-invent the wheel. Rather, we should find out what is already being done by others for the age group we want to serve so that what we might offer can fit in.

Chapter 3 about dementia, in its various forms and stages, is hugely informative, enlightened and enlivened by stories of some of those Tina has encountered in her volunteering and professional experience. Having reviewed many books about dementia over the years I learned so much and was greatly moved by this single chapter.

The same story-based approach characterises the following chapter concerning the carers of those with dementia, some of whose voices are clearly heard in extracts from the letters they have written. This leads to five valuable guiding principles for churches in supporting carers and to signposting some helpful groups at work in this area.

Care Homes are the subject of Chapter 5 and Tina begin by challenging the assumption often made that they have little need of outside support, when manifestly staff are usually so run off their feet that there is little time for anything beyond meeting residents' most basic needs. Despite living with others, sight and hearing impairment and memory loss can mean that relationships are difficult to develop – and there is little that is worse than feeling alone in a crowd. There is therefore a huge role for volunteers to visit care homes. Tina points out that as there are more than four times the number of churches in the UK than there are care homes, there is real scope for the latter to be 'adopted' by the former, if the will is there. Tina supplies a short list of simple suggestions for churches to show their appreciation of and support for a local care home. It may not help our churches to grow but it will certainly help us show our Christ-given love for our often-forgotten neighbours!

The sixth chapter is concerned with church buildings and the relevant activities that can take place there – provided that access is clear and safe and that the spaces to be used can be made hearing and sight-loss friendly, and that volunteers are dementia-friendly. Suggestions are made regarding a whole variety of groups, whether exercise, computer, knit and natter, arts and crafts, life and Bible study, plus lunch clubs and holidays at home. Again, plenty of good examples and stories are shared, together with useful tips such as the importance of name tags and the power of food! (A further chapter is addressed to churches without their own premises.) Such activities and the relationships that they make possible can also draw attendees closer to a faith of their own. Indeed, mission is the subject of the following chapter which is written with great understanding, honesty and sensitivity.

Recognising the many possibilities that have been suggested for growing ministry amongst older people, Tina devotes her final chapter to 'Getting Started' which poses and unpacks three crucial questions: Where are we now? Where do we want to be? How are we going to get there? As I write we appear to be gradually coming out of the lockdowns that churches have struggled with and which have particularly affected older people. What better time to think through our preparations for 'the new normal' and what better guide?

Michael Jackson, 'Still Love Left: Faith and Hope in Later Life'
Youcaxton Publications (2021), £9.99

During the 26 years that Michael was Director of the historic St John's Winchester Charity he was responsible for establishing two nursing homes, one for those with physical needs and the other for those with mental incapacity including dementia. Following 'retirement' in 2013 he served in two appointments as a non-stipendiary Anglican priest. This book is the fruit of his long involvement with older people and much reflection on their spiritual needs. He takes a broad view of 'spirituality', recognising that there is 'a creativity in God's spirit within us which never dies' but also that a 'faith based' spirituality can greatly enrich later life.

I liked his contention that spirituality is the poetry of the soul and religion the prose. This is well illustrated by the plethora of quotations not just from the Bible but from a wide-ranging cross section of other sources.

In brief, his book comprises just over a hundred pages of text, followed by a brief bibliography of sources that have particularly informed his own reflection and a not too lengthy collection of end notes to each chapter. The layout is helpfully clear: there are three main parts relating respectively to the past, the present and the future, each comprising four chapters of seven to ten pages. Much of the content relates to healthy ageing so this review comments primarily upon its relevance to persons with dementia and their carers.

Making Sense of the Past: chapters on Identity, Loss, Reconciliation, Wisdom. Jackson rightly acknowledges the immense contribution of our past to our identity and the value of reconnecting with the key landmarks in older age (though not to become obsessed with the past). This raises particular challenges for those with dementia and their loved ones. Since dementia in its early stages tends to affect more recent memory the stimulation of earlier memories is helpful, and Michael endorses the value of creating a 'memory box' containing meaningful objects from a person's past, which can stimulate conversation and be particularly helpful when they go into residential care. Old age tends to be marked by an accumulation of losses (e.g. ill-health, retirement from work, moving house, bereavements etc). Jackson found that when his mother struggled with the onset of Alzheimer's disease her sense of loss was deeply distressing, the only saving grace being that as her memory diminished so did some of her fears. The knowledge that death is that much nearer can give urgency to the need to find forgiveness and reconciliation. Jackson does not explicitly apply this to those with dementia though guilt and regret could well be exacerbating their condition and may be effectively addressed by means of patient listening, the offices of the church and bringing together those who have fallen out. Likewise, the accumulated wisdom of old age, too often ignored in current society and especially so of course in the case of people with dementia, needs to be affirmed.

Embracing the Present: chapters on Growth, Contentment, Engagement, Blessing. Jackson is quite sure that at the heart of living well as we age is a realization that spiritually we can go on growing and learning and remain as active as ever, renewed daily by God's grace. This may seem less applicable to those with dementia, though many people testify how they have learned so much from such people. However, living with dementia is often an agonising experience far removed from finding any plateau of contentment. It has to be said though that the spirits of people with dementia can be greatly lifted, at least in the short term, by the company of those they love or being transported through music and that there can often be peace at last. One of the contributors to contentment that Jackson asserts is a sense of humour and this is often retained by those with dementia, in relation both to the ability to laugh at themselves and with other people.

I remember one person who led regular meetings in a dementia care setting who on a particular occasion went to the hairdresser before the meeting and by mishap her hair ended up bright orange; the shared hilarity at the care home was unrestrained and enheartened everyone!

Facing a Certain Future: chapters on Acceptance, Passion, Death, Resurrection. I, at first, thought the title of this third part should have been 'Facing an Uncertain Future' but quickly realised that the certainty refers to both the inevitability of death and the Christian belief in the passage to a life to come. Jackson found that the older the residents at St John's became the more they seemed to have the gift of taking life as it comes. He notes that acceptance involves taking the rough with the smooth and requires resilience, patience and knowing when to let go. Perhaps more relevant in regard to those with dementia is his interpretation of 'passion' not as extreme emotion but identifying with Christ's suffering and death, accepting utter dependence upon others and God.

Writing again of his mother he tells how he so often found well-meaning friends asking 'does she still know you?' with the likely sub-text implying there could surely be no ongoing relationship. He felt assured that in his love for her he had been called into her passion and that whatever the ravages of Alzheimer's he never felt that he lost touch with her personhood. Jackson is inspired to view the end of life through Jesus's last words on the cross in John's Gospel, 'It is finished', meaning completed, perfected. This, ultimately, depends upon the love of God and 'those who like my mother have died having lost voice and mind during their earthly life will be re-membered by God'. Mindful of this we can all 'have love left in our heart'.

Robin Thomson, 'Living with Alzheimer's: A Love Story' Instant Apostle (2020), £8.99

This is one of the latest in a growing number of books by persons with dementia in its various forms or by their loved ones. They all seek to tell it as it really is in their experience whilst acknowledging that each will experience the disease in a unique way.

Robin Thomson certainly tells a fascinating story. His wife-to-be Shoko was born into a well-regarded Japanese family just north of Tokyo but during the second world war lost both her parents by the time she was 12, thereafter being brought up her grandparents. Having become a Christian, Shoko trained at Moody Bible Institute in Chicago and London Bible College, eventually meeting Robin who was on his way to Madras as a missionary. They married in 1969 and the book recounts much in the exciting, fulfilling and truly challenging 20 years the family spent in India

In 2012, when they were living in Raynes Park, Shoko was diagnosed with Alzheimer's disease at the age of 81.

With the aid of the journal Robin kept and copies of the letters he sent and received, he charts the journey that the family had to make beginning with an almost blank sheet in regard to their knowledge of Alzheimer's. In some 16 short chapters he highlights so many developments that were significant. Let some of the chapter headings whet your appetite: Losing things One by One. Closing Doors. Joined-up Support? Three Solid Pillars. What Was So Difficult? Is This the Same Person? 'You're Not My Husband'. Ready for the Long Haul? Going Home. But do read the whole book which is moving, at times really uplifting, and above all utterly honest.

Having read 'Living with Alzheimer's' twice now some things particularly fascinated me. First, how music was all-important to Shoko. Indeed, Robin refers to this the whole way through his book because at every stage she loved to sing: along with Robin, with several of her day carers and other visitors or in church, and whether in Japanese or English; hymns were important to her as were traditional songs from her native country.

Interestingly, Robin found that Shoko tended to favour singing and speaking Japanese as her dementia progressed, so much so that he regretted his own limited ability in that tongue. I was reminded of a Welsh medical professor I met during my ministry who in advanced dementia no longer spoke in English but entirely in his first language.

I was very impressed at the support that the couple evidently received from their Anglican church which they continued to attend following the diagnosis of Alzheimer's. Shoko always felt at home there and loved the vicar who became a cherished mentor of Robin. A good number of church members became regular visitors. If only all churches were as welcoming, understanding and practically supportive!

The last 50 or so pages within the Reflections bring everything together. First, Thomson pinpoints the 'holes in the system' he has experienced and humbly suggests how improvements may be made, whilst in the meanwhile families need to build up their own support teams. Next, he answers the basic question, 'Is anybody still there?' with a resounding yes: 'Our self goes on living in relationship with others, and also – if we believe it - in relationship with God', for we are held in his memory.

Thomson was much moved and sustained by the way in which, up to the end and despite everything, Shona would assure him of her love. He is totally convinced that 'there is absolutely no substitute for a loving relationship'. There follows an Appendix in which Thomson summarises 'What I Wish I Had Known Sooner or Done Better' ending with 'But there were some things that we did get right...'

Finally, he lists the resources he has found useful, some of which he discovered only after Shoko died, and all of which I would endorse.

Networking

On June 16, Anna Chaplaincy issued a post headed 'changing ideas on dementia' relating to an article, 'How to blunt the claws of dementia' published in the *Church Times* on 11 June. This looked at how churches can help lessen the isolation experienced by people with dementia. National Church Lead for Anna Chaplaincy Julia Burton-Jones, and Churches Together in Cumbria Anna Chaplaincy lead Katherine Froggatt, were interviewed for the article.

Professor of Sociology of Ageing at UCL, Paul Higgs, spoke about his research on how one of the main denominations viewed dementia, saying that 'the families of people with dementia were subject to a kind of 'othering'. 'The hierarchy says that the church has to deal with dementia, but in practice the ministers weren't interested, because they couldn't see how it would grow their congregations.' Julia shared ideas for churches for including people with dementia and Katherine said, 'In a sense becoming dementia-friendly is about becoming everybody-friendly, because it's saying: There's space here for you, whoever you are.'

Examples of activities for people with dementia in Rochester and Lichfield dioceses mentioned in the article include dementia cafes, singing groups and carers' groups, as well as inclusive services. Julia said, 'We need to feel comfortable with people with dementia. So much anxiety and uncertainty are born out of ignorance, which communicates itself to people with dementia and their carers as soon as they go into church. People aren't sure what to do; so, rather than do the wrong thing, they avoid the person with dementia.'

'Written words, spoken words can be elusive. Sometimes you might design a service with people with dementia in mind; but, as much as anything, it's about how you relate to them and accommodate their needs, and overcome their anxieties about saying or doing the right thing, and do our best to make them feel that we want them there.'

Resources

Journal of Dementia Care

The Journal of Dementia Care (JDC) has recently been re-launched under new ownership of a Charitable Community Benefit Society called 'Dementia Publishing Ltd'.

Led by Founder and Editor-in-Chief, Dr Richard Hawkins, and Managing Editor, Sue Benson, the Journal is published bi-monthly and available digitally to subscribers.

A free newsletter is also published, and the website is updated weekly with news and information relevant to people working in dementia care in all settings.

A charitable Community Benefit Society is a relatively new model, whose purpose is to support a 'community of interest', funded by social investment, and in the case of the Journal of Dementia Care, subscriptions too. JDC and the UK Dementia Congress has a strong community following built up over many years, bringing together practitioners, researchers, family carers and people with dementia themselves – everyone who cares passionately about dementia care and the vital importance of supporting all who work in the field.

Experts working in the field of dementia care have endorsed this new era for the Journal.

Jude Sweeting, Director of *Dementia Pathfinders* and Chair of *Resonate Arts* said:

"JDC is the 'go to place' for any dementia practitioner or dementia team, either wanting to improve themselves or wanting a question answered about what works best. And for employers it's a low cost, high value way to nurture and develop their workforce. It really does sustain those who thrive on ideas and are willing to imagine, to try and to give more".

If you would like to subscribe to the Journal of Dementia Care, or simply sign up for the free newsletters, you can find more information here:

www.journalofdementiacare.co.uk

'My Faith Matters': a resource for churches

Produced by Livability, a Christian charity supporting people with disabilities to live the life they want to live, 'My Faith Matters' is a resource to support and enable people living with dementia to capture and celebrate their faith journey. Formatted as an A4 booklet, 'My Faith Matters' guides people to record significant memories and information that is important to them in their spiritual life, to help family members and friends, support networks and faith communities to understand each person's unique needs and wishes.

Designed to be completed in conversation with the person living with dementia, 'My Faith Matters' contains a simple template and helpful guidelines to support the process and ensure that the information recorded reflects the person's spiritual aspirations and needs.

A pdf of 'My Faith Matters' can be downloaded here: [Livability-Dementia-Inclusive-Church-Web.pdf](#)