



Dementia Newsletter

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A letter from the vice-Chair of *Christians on Ageing*

Dear Readers

As we live through weeks of lock-down designed to limit the spread of covid-19, it has become difficult to be sure what day it is, or to remember what has happened when. Difficult to give attention to other issues which are important in the long run.

We have encouraging news from Alzheimer Europe that the prevalence of dementia (rate per population within age-bands) has fallen. We have learned that some factors predisposing people to the development of dementia can be subject to effective interventions: high levels of air pollution increase the risk, exercise and sensible diet and less stressful lives are associated with less dementia. A National Strategy for Healthier Lives will move things further in this positive direction as, hopefully, will the government's 'Moon-shot' for dementia research.

NICE has been, perhaps surprisingly, pleased with the care available to people with dementia and their families. 'John's Campaign', successful in improving knowledge and care in hospital wards, is being extended to care homes. All manner of good.

But then we have the covid-19 crisis. Starting with a report to WHO December 31st, this phenomenon has dominated the world: first China and now spread to more than 200 countries across the continents. We have learned that the infection affects certain groups more than others: older people - where the death rate is higher amongst those over 70, men rather than women, certain ethnicities, and people with underlying conditions - amongst which is dementia, second only to heart conditions, of the pathologies mentioned on death certificates which feature covid-19.

The crisis had revealed naked ageism in several quarters. Caring for people with dementia has become doubly difficult because of the restrictions to social contact where people are being cared for at home. The situation in care homes has revealed examples of great ingenuity amongst staff to maintain care and entertainment and to inform families of what life is like in the home, even though they are not allowed to visit. Staff have been heroic, though some have had to withdraw because of self-isolation or having the illness themselves. Protective clothing has been in short supply. For several weeks the UK excluded deaths in care homes from the covid-19 statistics. It is now clear that here, as in other countries, there is a high death rate amongst residents, many of them with a combination of dementia and covid-19. The toll of stress on families and staff is immense – even at the very end of life people have not been allowed to visit. Funerals occur but are much restricted in who can attend and what can be done.

When this crisis is over, we will be seeing a much altered landscape compared with that of December 2019 – The changes and consequences will be greatest in the community of people with dementia and their families and care professionals

David Jolley

NEWS

At the end of October 2019, it was announced that doctors in the US had launched a clinical trial to discover if **exposure to flickering lights and low-frequency sounds** can slow the progression of Alzheimer's. The study is led by Li-Huei Tsai at the Massachusetts Institute of Technology and follows the discovery of the clearance of protein plaques and tangles in mice by such exposure.

Interviewed on the BBC Today programme on 23 November, health secretary Matt Hancock stated that he intended to **double the financing of dementia research** if the Conservatives were returned to government at the December election. He said that whilst great progress had been made in research into cancer, heart attacks and stroke, the same was not so in dementia. Whilst people were living longer many were afflicted with dementia in their later years. Hancock remains health secretary.

In late November we received news from Dementia Carers Count (www.dementiacarers.org.uk) that it has recruited a new associate director of development, Mankit Yau, whose main task will be to create the UK's first specialist Dementia Carers Centre in the Midlands. It will be fully dementia-friendly and should be fully operational by 2022. Formerly the 150-year-old Royal Surgical Society, the charity re-launched in June 2018 under its new name and already offers one and three-day courses and other resources for family carers.

A breakthrough was published in the December issue of the journal Nature Communications. Researchers at Bath University have created **artificial neurons** that could potentially be implanted into patients to treat paralysis, a specific form of heart failure, and restore failing brain circuits in those with dementia.

The Michaelmas Term issue of The Cambridge University Alumni Magazine featured the work of psychiatrist and neuroscientist Professor Ed Bullmore who is pursuing a **new approach which links obesity with Alzheimer's, cancer and autoimmune diseases** and argues that inflammation is the common thread since the emergence of such diseases often appear following a predictable time period, giving hope that cellular changes may be able to be halted and repaired.

Amongst a number of articles focussing on the biology of ageing published in late December, **Amelia Hill's 'Scientists harnessing AI (Artificial Intelligence) to reverse ageing in billion-dollar industry'** deserves particular attention (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5943638/>). She reports on the work and beliefs of Nir Barzilai in New York who is looking for more definite proof that metformin, an inexpensive medication prescribed for Type 2 Diabetes, can extend life-expectation and slow the development of cancers, Alzheimer's disease and heart disease.

In the New Year, the journal Science Translational Medicine contained a report on research by the University of California, San Francisco, which involved 32 people aged between 49 and 83. PET scans were taken at the start of the study along with an MRI, which reveals the structure of the brain, and another MRI after 15 months. This revealed that the **level and location of tau tangles** were closely linked to the shrinkage of grey matter in the brain.

On 13 January 2020 The Guardian reported on a nine week visit to Thailand by two professors of geography, Caleb Johnston of Newcastle University and Geraldine Pratt of British Columbia University, during which they studied the extent to which families of relatives with dementia are **sending their loved ones to Thailand** for care because they cannot afford adequate care in the UK, the cost of which is cited as up to £700 a week in local authority homes (of which there are now few) and around £1000 for private care. With ever-increasing costs in our 'failing and ailing system' the Thailand option may become more popular.

A **study of 12 papers** in English published between 2007 and 2018 reported in the journal BMJ Open in January showed that 31% of people with dementia being supported in the community and 42% of those in care homes were at risk of receiving inappropriate medication.

On 7 February The Guardian, reporting on the return of female astronaut Christina Koch after 328 days on the international space station, stated that her **research during the mission** included growing protein crystals for potential use as treatments for Alzheimer's disease and Parkinson's.

On 24 February the National Association of Care Catering encouraged the extension into care homes of 'John's Campaign' which has highlighted **greater involvement of family members and friends** in the practical care of those with dementia in hospitals, not least in eating together.

In late February the Football Association decreed that children aged between six and 11 should **no longer be allowed to head the ball during training sessions**. This is to protect children from incurring brain injuries that might lead to developing dementia in later life, as witness the experience of professional footballers such as the late Jeff Astle, Nobby Stiles, Matt Tees and Chris Nicholl. Significantly, up until the late 1970s footballs were made of heavy leather which gained considerable added weight when used in rainy conditions.

In early March Professor Lillianne and team of Stony Brook University in New York reported finding that a **low carbohydrate diet** may prevent and even reverse age-related damage to the brain. Using brain scans of almost 1,000 individuals aged 18-88 they found that damage to neural pathways accelerated depending on where the brain got its energy from: glucose decreased the stability of the brain's networks whereas ketones, produced by the liver during carbohydrate restrictive diets made them more stable. These findings merit further investigation.

On 13 March The Daily Mail reported that **Four Seasons**, the UK's second largest care home provider with 16 thousand residents. **had transferred 58 of its homes** to other providers. Such changes cause anxiety, especially for those with dementia and their carers.

A new study reported on 30 March 30 the Swedish Karolinska Institutet found that people continuously **exposed to air pollution** are at increased risk of dementia, especially if they also suffer from cardiovascular diseases. Therefore, patients with cardiovascular diseases who live in polluted environments may require additional support from care providers to prevent dementia, according to the researchers.

In the wake of the news that 15 residents in a Luton care home had died, in all probability from the corona virus, the BBC Today programme on 9 April featured the concern voiced to the Health Secretary by the Alzheimer's Society that **those with dementia were being unfairly marginalised** by the present government approach to the disease. Apparently 70% of those in care homes suffer from dementia and there were particular difficulties faced by the residents, care staff and relatives. The availability of protective equipment was limited and it has not been the practice to test either residents or staff to date. 'Vicky' spoke movingly of the way in which she has had to communicate with her partner 'Arthur' through a window, which he could not understand, and had been told by the care home that she could only be allowed a single visit wearing protective clothing before Arthur died. Kathryn Smith advised relatives not to be pressured into signing end of life plans on behalf of their loved ones in care. Sam Monaghan, CEO of MHA Care Group (Methodist Homes), now the largest charitable care provider in the UK, urged the government to step up the pace regarding equipment and testing in the care sector and described how **MHA seeks to maintain normality in its homes** through continuing activities including music therapy and giving relatives access to their loved ones via windows, phones, Skype etc.

At the time of our going to press the situation has become graver because residents transferred to hospitals suspected of having the virus have often been sent back to their care homes without testing. Sadly, GPs seem unwilling to visit homes to provide death certificates which may or may not list the virus as the main or a contributory cause of death. This situation has been a main cause of **government data being likely to underestimate the numbers of UK deaths**. The government press conference on 22 April revealed that in England over two thousand residents in care homes have died since the start of the pandemic and that the number had doubled between April 10 and 15; in Scotland such deaths comprise a third of all deaths there.

NEXT: Book reviews by Brian Allen, Albert Jewel and David Jolley

BOOK REVIEWS

Dementia-Friendly Worship: A Multifaith Handbook for Chaplains, Clergy and Faith Communities, Lynda Everyman and Don Wendorf, senior eds. (2019, Jessica Kingsley Publishers, 326 pp, £25)

For decades I held the belief that I did not want to visit the United States of America. It was only when one of our daughters spent a year there as part of her undergraduate course that I took the plunge. As soon as we arrived, I realised that I had nurtured an unnecessary resistance. I recognised a little of that old resistance emerging when contemplating this book. It is a series of nearly fifty short pieces, mostly very practical in nature, with some forty-four American contributors.

Inevitably there is a fair amount of repetition in a collection such as this and at times I wished the editors had intervened. Given that there is no explicit attempt at being systematic inconsistencies do arise. A strong plea to use the USA's Alzheimer's Association's preferred 'care partners' rather than 'care givers' and 'receivers' is countered elsewhere by an unquestioning use of the giver/receiver relationship. It would have been helpful to have encountered comment on the use of the concept of being 'dementia friendly', sometimes criticised for being patronising, rather than being dementia 'active' or 'inclusive'. Most references are to 'people living with dementia' but occasionally 'dementia patient/sufferers' occurs. Whilst there are some moving and at times inspiring accounts of being with people living with dementia there are also some rather didactic proposals. Some descriptions of worship appeared to be quite prescriptive. For example, an Ignatian spirituality exercise may well be a useful tool if practitioners are used to it and know the people living with dementia well enough to anticipate its appropriateness. As is always the case what 'works' in one situation is not necessarily transferable or replicable in another context.

Alzheimer's disease is commonly referenced, and occasionally other forms of dementia are mentioned in passing. In some contributions it reads as if there was a very limited understanding of dementia per se including the suggestion that (only) some dementias are progressive. Perhaps there would have been some benefit in including an introductory overview and signposting to sources of authoritative information about the disease, its many forms and contents. The caveat that if you have met a person living with dementia then you have met just one person living with dementia is well made.

There are four main sections to this very recent publication: Introduction to Dementia Friendly Worship, Voices of Persons Living with Dementia, Worship Services and Beyond Worship: Dementia-Friendly Faith Communities. Nonetheless the voices of people living with dementia echo throughout most of the book and vitally so. This is about being with rather than doing something to or for people living with dementia, a theme which bears repetition. I certainly soon recognised and appreciated from my own experience the authenticity of much of the narrative based accounts of sharing worship in its broadest sense with people living with dementia.

Sound advice was clearly stated by some contributors. Practitioners should avoid the temptation to proselytise or theologise when sharing time and worship with people living with dementia. They must stay focussed and be present in the moment, prepared to embrace the reality of those living with dementia. All the senses should be employed creatively as should appropriate communication skills including sharing companionable silence. These might seem self-evident to experienced practitioners and hopefully will not appear too radical to those who have been trained to offer pastoral care and worship. However, they are all points well-made and act as a balance to some of the rather more prescriptive contributions. I felt my age when the usefulness of an i-phone (sic. Other smart phones are available!) when ministering one to one was advocated. Much of my own experience pre-dates the universal availability of such technology when I found myself humming or singing in such situations.

The majority of contributors come from the Christian tradition, but other faith traditions are represented here, too. The Sikh contribution is a nice balance between an introduction to Sikhism, an assertion that everyone living with dementia and their progression through the disease is different, and how Sikhism might respond. References to Buddhism, meditation and mindfulness occur in several places throughout the text. In a section dedicated specifically to Buddhism a long-term meditator in the Zen tradition told his wife in some moments of lucidity 'This Alzheimer's, it's not to be worried about. It's a different truth.' This is reinforced elsewhere by a Roman Catholic contributor living with dementia who focuses on the Biblical invitation to 'Be not afraid', applying this to family and others affected by dementia. Recognising that fear is often about the unknown, faith communities are encouraged to learn about the different forms that dementia takes and to ask open questions of people living with dementia. This approach is more about exploring the mystery rather than trying to fix the problem (as, for example, Christian existentialist Gabriel Marcel advocates elsewhere or Teilhard de Chardin's *Le Milieu Divin*). Here the subjectivity of the person living with dementia is the focus rather than the disease itself.

Given that this is an American publication it is worth asking how transferable are the insights and proposals it contains. One thing that struck me quite forcibly was the reference to Memory Care facilities and some large, that is over one thousand residents, villages or communities for older people including those with cognitive impairments. There is considerable stress on memory with little recognition of some of the other features of dementia. Because memory is often the main focus perhaps some discussion about the location (for example, the individual, community, tradition or place) and possible types of memory (for example, explicit recalling 'what' or implicit recalling 'how') would have been helpful here.

Several mentions of non-denominational ministers suggest a different context from the UK where black and other minority ethnic demographics are clearly different, too. Worthy of note in this respect is a very engaging account from an Indian American perspective describing how everything and everyone is connected and God is at the centre.

Finally, what is missing which might well have featured in an equivalent UK collection? I imagine that the use of memory boxes, Godly Play and life stories would have played a part. I would certainly expect the inclusion of ministers and volunteers needing to be subject to safeguarding measures to ensure the protection of the vulnerabilities of people living with dementia.

I have valued the experience of spending time with people living with dementia for what that teaches me about humanity, mine and theirs: the recognition of our need for one other is central. The insights gained from considering worship and people living with dementia does raise the question as to whether many of the considerations covered in this interesting publication should not apply to worship with everyone and not just people living with dementia.

Brian Allen

Newcastle upon Tyne

'Art Therapy with Older Adults' by Erin Partridge (2019, Jessica Kingsley Publishers, pp148, £18.99)

Erin Partridge is peculiarly well equipped to write this innovative and stimulating book. She explains how she has been influenced by long-living members of her own family, her training as an art therapist culminating in her 2018 PhD dissertation (*'Amplified voices: Art-based inquiry into elder communication'*) and most of all her extensive work with older people in US assisted living facilities.

She clearly sets out the philosophy that underlies her practice: that skilled art therapists can help change the prevailing tendency for care and medical staff to do things for residents (their 'patients') and thereby undermine the dignity and fulfilment they can derive from continuing to express their own creativity. Some of her work is carried out on an individual basis but working with groups can be more rewarding in terms of inter-personal communication and mutual encouragement. She believes and shows that this applies just as much for those living with at least the early and middle stages of dementia because they are often the people who feel most marginalised in our communities. Hence the sub-title of her book: *'Connected and Empowered'*.

The author distinguishes between art specialists who may be good at giving talks, activity organisers who may venture no further than Bingo sessions and factual quizzes (which can disadvantage those with memory loss) and art therapists who can act as facilitators for older people and help them discover (or re-discover) and express their creative gifts, which they may often be able to relate to their own life experience.

The detail of the book, the main text of which is only 120 pages long, is impressive, from the need for an appropriate space for activity to exemplary case studies (many of which

are of persons with dementia and are moving to read) and appendices for session planning and reporting. I like Partridge's emphasis on the need to give participants time as well as space since older people are more prone to sight and hearing deficits and can be slower to find words to respond. In the later part of the book Partridge shows how venturing out of their care home to look at murals and spend time in museums and art galleries can be most rewarding for participants, especially if the places visited are willing to make special provision for their access and accommodation. Most interestingly, Partridge has at times been able to work along with art students who, to their surprise, have often attested to learning so much from the insights and contributions of their elders - as indeed does the author herself.

There is an extensive reference section and an excellent index. Many of those she refers to are North American, and strangely very few are other Jessica Kingsley authors. One may argue that the American facilities appear to be more accommodating and doubtless more expensive than those in the UK, but Partridge had to fight hard to effectively challenge the prevailing philosophy and practice and persuade others of the value of her approach. We have much to learn from her. And it is worth noting that in this country MHA Care Group (Methodist Homes) has made available music therapy throughout its dementia care homes. Perhaps the same can happen with art therapy, at least on a trial basis.

Albert Jewell

Living with Alzheimer's (2020, Instant Apostle, pp187, pb £8.99)

The life of Robin Thomson and his Japanese wife Shoko, who died of heart failure in 2018, is by any account fascinating. First meeting on board ship from Marseilles to Yokohama in 1966 they subsequently married in Madras, where Robin taught at Hindustan Bible Institute, remaining in India for some 20 years, frequently moving house and facing the challenges that living in an unfamiliar culture inevitably brings. Daughter Sarah describes her mother as a great adventurer who was hugely energetic and competent during that time.

However, after the family eventually settled in Raynes Park, all this was to change. For Thomson's book describes their experience after Shoko's dementia diagnosis in 2012. The sequence of chapters, Losing Things One by One, Closing Doors, Is This the Same Person, You're Not my Husband, An Increasing Sense of Loss, Ready for the Long Haul, tracks the progression of the disease and the gradual shrinkage of their world, although the author is fully aware that this will vary from person to person. A novel feature of the book is that in the final section the author has listed available resources in the order that he would have found most helpful. Of the 26 books briefly summarised all were written in the last eleven years - testimony to how far dementia has come out of the closet of late. The author learnt so much from the writers, one example being John Zeisel's advice regarding communication: because the other person is on a fixed course that we cannot change, we shouldn't say 'Don't' but rather distract, redirect, divert; 'easy to understand, much harder to practise'! (p83).

Robin is totally honest about his personal limitations and the mistakes he made in caring for Shoko, not least the irritation and anger he felt and expressed at times, something with which most family carers will identify. Sleep loss took its toll on Robin's health. He writes: *'The pressure was relentless. It wasn't Shoko's fault and I wasn't against her. But it was hard not to be impatient, easy to speak cross words, difficult to be waiting: to go out, to sit at the table, to get to bed. How long?'* (p78). Interestingly, he does not mention being exasperated by his wife constantly asking the same question, which is something often experienced by family carers. Although he has an elementary knowledge of the Japanese language he regretted his lack of fluency as his wife reverts to her first language. Although this is not something that will be shared by many other carers I well remember when I was a minister in Wales two eminent medical professors who were church members similarly reverting to their first language, Welsh, in advanced dementia.

Robin's honesty is also reflected in the challenge that Shoko's condition brings to his Christian faith. Most frightening of all is the feeling that the person he knew and loved before she developed Alzheimer's may no longer be there. He is forced to ask of a supposedly all-loving and all-powerful God 'Why?' He finds no easy answers but is sustained through conversation with his vicar by the assurance that when we suffer, God is with us, and that we have hope because our relationship with God continues beyond death. He finds consolation in Professor John Swinton's conclusion that *'We are not just minds, nor is the higher cortical part of us all that is our self...As people made by God...we are held in God's memory. God does not let us go and therefore we continue to exist, even when we ourselves may have forgotten everything, including God'* (pp162-3). At a more down to earth level Robin wrestles with Jesus' words 'do not be anxious about tomorrow' and struggles to learn to be thankful for each day as it comes.

The final four chapters of this sensitively written book comprise 'Reflections' on Robin's whole caring experience. He identifies some of the holes in the care system which mean that access to support services varies greatly from place to place and in quality, so that finding a way forward is always challenging. Everyone he spoke to told him that he would not be able to shoulder the burden of caring on his own; he needed to find support from a mixture of professionals, family, friends, care groups and church. He recognises that he has been fortunate in this regard and that, although not rich, he has been able to afford the cost of extra care when necessary. Finally, the book climaxes in the chapter on The Power of Love, a love for which there is absolutely no substitute, which is expressed through body language and doing things together more than words (singing remained important for Robin and Shoko), and which enables a new relationship to be forged in the changed circumstances that Alzheimer's brings. Fittingly, the closing words of this chapter are 'Perfect love casts out fear' (1 John 4:18).

Albert Jewell

The above review first appeared in The Methodist Recorder on 21 February 2020 and is used by permission.

The Inflamed Mind by Edward Bullmore. (2019, Short Books, London, pp240+104 refs, p/b £8.99)

Edward Bullmore has been Professor of Psychiatry at Cambridge University since 1999. He came to psychiatry via education at Oxford and St Bartholomew's Medical College, training as a physician with a strong history in research. He has retained involvement in the pharmaceutical industry.

This is a game-changing book. Bullmore uses reflections on his own experience of illness, and the experience of patients he has met and treated, to bring together a new synthesis of how body and mind relate in illness. He probably overstates the view that medicine had been stuck in a Cartesian dualism of the separateness of physical and mental/spiritual disorders until recently. Holistic medicine has a long and respected history which goes back to the Romans and beyond. But what he brings us is a clear and persuasive exposition of new insight into the working of the immune system: its power for good in combating infection and trauma, its potential for harm when the inflammatory process misreads matters and turns against components of the self, and its influence on brain function.

Inflammation utilises responses from white blood cells (macrophages) and proteinaceous antibodies in its fight against infection or trauma. It has long been understood that neither macrophages nor antibodies can affect the brain directly because they are excluded by the Blood Brain Barrier. Yet we know that people often feel 'off colour' or depressed in association with illness where there is local or generalised inflammation. This is because, when macrophages are activated, they release cytokines, hormone-like chemicals which tell other parts of the body that an inflammatory response is underway and they may need to take action. Importantly cytokines pass through the Blood Brain Barrier and activate microglia within the brain. Activated microglia may turn against nerve cells and synapses near to them, causing malfunction or destruction.

Bullmore dismisses Descartes, but with due respect, and Freud and his ilk, with less respect, before marshalling evidence in support of the hypothesis that changes in the physical substrate of the brain explain the phenomenon of depression, and other mental disorders. His strongest suit begins with the story of Iproniazid, a monoamine oxidase inhibitor which was created to treat TB, but extended its career by successful treatment of depression, spawning an army of similar drugs which have been followed by SSRIs – Selective Serotonin Inhibitors. So, depression can be seen as due to a lack of catecholamines in the brain.

Recent research has found that high levels of cytokines and other inflammatory markers in blood are associated with depressive symptoms during and after infections. Smaller rises in cytokines and inflammatory makers occur during depression in the absence of infection or recent trauma. When depressive symptoms resolve, so do the markers of systemic infection. For Bullmore this poses the question: Have we discovered the basis of a unitary explanation of depression? Is it a component of an inflammatory response – sometimes to infection or trauma – but also as an autoimmune phenomenon in producing depressive disorders?

This raises the prospect of strategies to reduce the incidence of depression by avoiding inflammatory settings such as stress, obesity and poverty as well as infection and trauma. It also encourages the idea that treatment with anti-inflammatory medicines can ameliorate or reverse depression. There is some evidence that this does work. The possibility of engineering substances which counter the effects of cytokines has already been demonstrated to great effect in rheumatoid arthritis. Maybe this will be how a new generation of antidepressants will be produced. An almost quirky revelation is that stimulation of the vagus nerve, by scratching your ear lobe, or by use of an electrical stimulator, suppresses the release of cytokines by the spleen. This reduces a tendency to indigestion, and also reduces depressive mood.

There is an obvious relevance of Bullmore's hypothesis for dementia in that there is an association of inflammation with Alzheimer's disease which treatment with anti-inflammatory medication can potentially reduce.

Much to be pondered in this fascinating review of current thinking

David Jolley

NETWORKING

Faith in Later Life

The evangelical organisation *Faith in Later Life* (FILL) has published on their website an exploration of 'What happens to faith when Christians get dementia?' It is written by Tricia Williams following completion of her PhD supervised by Professor John Swinton of Aberdeen University and is available on the Faith in Later Life website.

Time to Telephone Befriending

A service supporting people living with dementia and memory loss during the season of Coronavirus and beyond, *Time to Talk Befriending* (TTTB) is a Brighton & Hove based charity founded in 2013, following a church social action project, which identified the damaging effect of loneliness on older people's wellbeing. TTTB supports over 350 people across Sussex, through regular events, one to one befriending, Anna Chaplaincy, and during this time of increased physical distance, friendship phone calls. Regular phone calls provide a great opportunity for social connections and friendship, and whatever our age, having a friendly chat on the phone can be the highlight of our day. At this time, church families and pastoral teams may find they are making far more phone calls than ever, and when supporting people living with dementia this can feel quite daunting if we think that someone might not know who we are, or that keeping conversation flowing might be difficult. Time to Talk Befriending is delighted to share some **Guidelines and Top Tips** with *Christians on Ageing* on how to have better conversations with people who are living with dementia, and those who are experiencing memory loss.

Guidelines and Top Tips for telephone contact

Developed in collaboration with Story Chaplain, Charlotte Overton-Hart, who is an expert in the field of dementia.

1. Moments over memories

If a person is living with dementia or memory loss, asking what a person has done that day might be tricky to answer. The goal of the phone call is enjoy time together *in the moment*, and to give the person you are calling your full attention. Rather than asking what they have done that day, asking, 'How are you doing today?' creates more of an opportunity for someone to answer without having to share memories which may be difficult to recall. Why not take the opportunity to do something together during your phone call, like looking out the window wherever you are and describing what you can see, reading a poem, prayer, or passage from the Bible together. The key here is doing something *together*.

2. Will the person I call be able to remember we have spoken?

If a person is living with dementia it may be difficult to recall the content of a phone call, or even that the phone call has taken place. That said, more and more research is confirming that a good interaction and happy time can positively impact a person's mood long after that interaction, even if they aren't able to recall what the interaction was. Your call *will* make a difference to a person's quality of life.

3. How do I know what the right length call is?

When a person is not living with dementia we would suggest 30 minutes as a guideline time, but if a person is living with dementia their concentration span may be more limited, or a call of this length could be exhausting. Play it by ear, keeping in mind that a person's energy levels may be different at different times of the day, and also from one day to another.

4. I feel like I'm talking a lot, and the conversation is drying up.

You may find that your conversation comes to a natural end after 15 minutes or less, even if you have made a note of possible topics of conversation. That's OK. It's more important to let someone know you are thinking of them and glad to be in touch with them than staying on the line in awkward silence.

5. I can barely get a word in!

You may find that having a listening ear is all a person needs, and they are keener to chat than to hear from you. This is understandable, especially if you are the only person who is calling 'just for a chat'. Make a note of the topics the person you are calling especially enjoys talking about and return to these during future phone calls.

6. Is it OK to talk about the same things again?

Yes! The goal of your time is to create a positive experience, so if you discover that the person you are calling enjoys talking about a particular topic - whether this is their cat, a particular aspect of church life, or a particular time in their life - do return to this as much as they are happy to talk about it.

7. What happens if the person I'm calling gets anxious or upset during the call?

We all have good days and bad days, whether or not we are living with dementia. If the person you're calling shares how they are feeling, the most important thing is to listen and not dismiss their emotions. Rather than straightaway trying to distract a person from feeling low, acknowledge how they are feeling, before gently introducing a different topic of conversation. If you feel able to, offer to pray together, or perhaps read an encouraging passage from the Bible.

8. What happens if the person I'm calling asks for something I'm not able to help with or I don't know the answer?

Anything you're not sure about, share that with them and let them know you will check in with someone on your church pastoral team and you'll get back to them. A simple, 'I'm not sure about that, but I'll do my best to find out' should reassure someone that you have listened to their questions and concerns and you will try to find an answer.

9. How do I explain the current Covid-19 situation to a person with dementia?

If Covid-19 comes up, explain the current situation to the person with dementia using simple and short sentences that you can repeat if needed, rather than trying to explain things in detail. Try not to speculate about what the future may hold. Instead, focus on what we can all do now and in the coming days to stay safe and connected. Be sure the information you are sharing is clear and up-to-date.

10. Possible prompts / structure for your phone call

- Hello [person's name], it's [your name here] and I'm calling from [name of church / group], calling for a chat, and to see how you are.
- Is now a good time to speak? (Offer to call back if now isn't a good time)
- How are you doing today?
- How are you feeling today?
- Is there anything you need at the moment? (food, toiletries, prescription, etc)
- Are you sure? (asking a second time let's a person know you aren't just making small talk)
- Are you getting about the house OK? (Why not try some gentle exercises / stretches together)
- Are you managing to make meals OK at the moment?
- Are you finding anything a bit tricky at the moment?
- Where are you at the moment? (Living room, kitchen, hallway, etc.)
- What can you see? (Pictures, ornaments, a view out the window)
- Is there an object or photo in your room you can tell me about?
- Are you near a window?
- What can you see from the window?
- Can you see any signs of the seasons?
- Can you hear the birds?
- What's your favourite season? Why?
- What are you going to do now? (Share what you plan to do next, for example, 'I think I might have a cup of tea...')

Finally, share an encouragement or good news story you have heard, perhaps about neighbourhoods pulling together and helping one another, or something church family related. Finish on a positive note and use the person's name when you say goodbye. It may seem like a small thing, but it can mean a lot.

- I've really enjoyed speaking with you.
- Is there anything I can pray for you about?
- I'm looking forward to speaking to you again soon.

Jotting down some helpful notes

- *Before the call* - have a think about some things you'd like to talk about and make a note of these. If you are feeling nervous about what you'll talk about then a list of possible topics can help to keep the conversation going.
- *During the call* - the most important thing is to be present during your phone call. If possible, minimise background noise, which could be a distraction, either for you or the person you are speaking to. Have a piece of paper to hand to make a note of anything that comes up that you might forget after the call.
- *After the call* - take a moment to reflect on how you feel the call went. Did the person you were speaking to particularly enjoy any topics of conversations? Were there any that weren't received so well? Is there anything to feedback to your church Pastoral or Safeguarding Team around any immediate needs for food, medication, or signposting to other services?

To make further contact, readers can get in touch with:

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Thank you for reading this Newsletter. If you would like to let other readers know of any initiatives in which you are involved, please contact the Editor.

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