



# Dementia Newsletter

No. 56 November 2020

This newsletter is produced twice yearly by the Dementia Network of *Christians on Ageing*. It is available free by email attachment or hard copy at £5 per annum. If you wish to receive a copy please contact [info@ccoa.org.uk](mailto:info@ccoa.org.uk) or Christians on Ageing at the address below

If you wish to copy material published in this Newsletter, please ask the Editor for permission and acknowledge the source in your publication. The Editor welcomes contributions and letters for publication in forthcoming issues.

*Editorial Address*

Revd Dr Albert Jewell

63 Moor Grange View, Leeds LS16 5BH

Tel. 0113-278-9438. Email: [ajj633@btinternet.com](mailto:ajj633@btinternet.com)

*Christians on Ageing* Registered Charity Number: 289463.

Registered Office: 'Stoneway', Hornby Road, Appleton Wiske, Northallerton DL6 2AF

Website: [www.christiansonageing.org.uk](http://www.christiansonageing.org.uk)

## **A letter from the Chair of Christians on Ageing**

Dear Readers

Life for people living with dementia and their families, and for the professionals and volunteers involved in their care, is dominated by the threat of Covid-19 and the restrictions on life imposed by governments in an attempt to contain its spread. There is dawning realisation that the restrictions and abandonment of routines of health and social care are having impacts at least as lethal as the virus.

Care Homes are identified as dangerous places to be, for residents, staff and other potential visitors. Movement of people from hospital to care home and of staff between Homes has been identified as causal of the initial spread of the virus. This has led to the exclusion of families and people providing 'inessential' services. Even in dying, people have been required to be apart from family. Fewer people have been admitted to Homes. More people are staying at home and the death rate there is higher than usual. There has been an increase in the employment of live-in carers. Fine words in tribute to the heroics being performed by staff, have not yet led to clear plans to improve their conditions of work. 'Immigrant' carers are not to be protected from planned legal restrictions. There are calls for a root and branch review of health and care services on the same scale as those of 1945 which gave us the Welfare State. Let us hope that these calls will be heard – such a review and revision would surely improve conditions for people with dementia, their families and carers and bring expenditure and resource allocation in line with needs.

Churches have only recently been allowed to organise modified services. Many of the activities usually conducted by church communities or within their walls, have become unavailable. There are many innovative attempts to provide contact and activities, usually via the internet but also using telephones, local radio or TV. Still we receive urgent requests for access to just something which people with dementia can cope with and gives diversion from the limited routines of home in isolation.

Research has shown that isolation is a risk factor for the development of dementia. It adds to the vulnerability of people with established dementia. Identification of risk factors, some of which are correctable, is the main message of hope to reduce the incidence and prevalence of dementia. Genetic vulnerability to the worst ravages of Covid-19 are linked to APoE status (which measures the most prevalent genetic risk factor for Alzheimer's disease) and more is understood about the relationship between diabetes and dementia. But it is music, dance, walking, time in fresh air and design of internal and external environment, which are most surely therapeutic.

Significant markers in the legal field find revision of DoLS (Deprivation of Liberty Standards) delayed – everyone too busy with Covid 19; Human Rights of people with dementia probably compromised – rules designed to protect people are imposed without consultation; and The Hague has ruled that Advanced Directives cannot be reversed by their author once she or he loses capacity, but still has views. Small comfort here. There have been many deaths. Losing Tom Arie and Barbara Pointon who have pioneered and inspired us for half a century marks the end of an era – but leaves us to carry on informed by the principles and practices they have given us.

Meanwhile – Christians on Ageing have a Conference Call on 17 November 2020: '*Supporting family carers and friends of people with dementia*'. The discussion will be chaired by Julia Burton-Jones of the Diocese of Rochester with a contribution from Dr Albert Jewell. Joining instructions are on the Christians on Ageing Website <https://christiansonageing.org.uk/conference-call-2/>

*David Jolley*

~~~~~

## NEWS

### **Covid-19**

Inevitably much of the news contained in this section is concerned with the Coronavirus pandemic, the spread of which went into over-drive after our last issue had gone to press. Now, despite government restrictions, the infection rate has been doubling every few days and is beginning to take a mounting toll on older people.

Identifying the most vulnerable groups has been an ongoing challenge. In late April *The Guardian* reported that (apart from those over 60 and especially over 80) ethnic minorities, migrant workers and the disabled were disproportionately affected. The government has subsequently set up an investigation into what may be the main reasons for this disparity.

In the Society pages of *The Guardian* on 1 June Polly Toynbee suggested that we should move back towards integrated and nationalised care across the health-social care interface and that all services should be free of means-testing. On 15 June she cited 'the care home tragedy' as a 'stain on this government' with at that time 22,000 excess deaths in homes and hospitals emptying older patients into care homes heedless of the consequences.

At the end of June Oxford University's Leverhulme Centre for Demographic Science. announced the availability of a new online Covid-19 tool which can supplement test-and-trace technology by highlighting which regions and local areas are most likely to suffer disproportionate potential infections and hospital demand in case of future infection spikes. Combining key data from multiple sources of known Covid-19 vulnerabilities, such as age, social deprivation, population density, ethnicity and hospital resources, the dashboard is accurate to a granular local level, enabling policymakers to target resources to the most at-risk areas. Given the changing nature of the virus, it also allows users to adjust for changing infection rates and hospital resource levels. And, crucially, it can be an effective aide next to test-and-trace technology, to ensure health care preparedness and effective monitoring.

### **Care homes and the virus**

MHA Care Group (Methodist Homes) is the largest charitable organisation in the UK field with some 4,400 persons living in its care homes, 3,000 in retirement living communities with flexible care, and over 11,00 in local Live At Home support schemes. As a former Pastoral Director of MHA (Editor) I enquired in mid-May and discovered that at that stage they had lost over 300 residents (the later total was over 400) and three staff members to the virus. BBC2's Newsnight on 3 June devoted half an hour to a study of the group with the willing cooperation of the chief executive and other staff members which revealed the reality of their experience and highlighted the desperate problems they faced. It was

powerful and moving to watch and one hopes that the government took due note of the issues raised. At the time of compiling this newsletter the dangers to care homes from the relaxation of some government regulations and the propensity for children and young people unknowingly to pass on the virus to older people is causing great concern.

Official data now show that almost half of all those dying in care homes from Covid-19 have had dementia. Figures issued by the Office for National Statistics indicate that 49.5% of deaths from Covid-19, between 2 March and 12 June, were of people who had dementia as their main pre-existing condition. Overall, 19,394 people with and without dementia died from Covid-19 in care homes over this period.

Care homes deaths led to wider concern stretching back into early May as revealed by *Guardian* items and readers' letters. Many correspondents drew attention to differing experiences in different countries reflecting different states of preparedness and spare capacity within care systems and not least the varied use of test and trace from an early stage in the epidemic. On 4 May the paper stated that because of the lack of necessary equipment some families felt that their loved ones would be safer elsewhere. On 20 May it reported that deaths in care homes was running at three times the usual rate for that time of year, deaths at home at one and a half times greater, and that 80% of these extra deaths were not registered as due to Covid-19. Richard Coker deplored the grim phenomenon of 'harvesting' - when danger comes to a population and takes the weakest and most vulnerable. It is becoming clear that spread of the virus between care homes has in part been transmitted by staff, often agency workers, moving from home to home to fill vacancies, sometimes continuing to work despite developing mild symptoms because they needed the money.

*The Guardian* on 19 May, noting that the value and standing of people providing social care has been clearly realised during the crisis, urged that this should ensure that they receive appropriate long-term appreciation and reward.

Amongst the better news *The Guardian* on 5 June welcomed a scheme whereby scout troops are becoming linked to care homes to help alleviate a sense of isolation - though this has been constrained by regulations regarding proximity at a time when even close relatives have found it very difficult to visit loved ones in care homes even when they were dying.

On July 10 a tweet from Alzheimer's Society, which was followed up on the BBC Today programme, revealed that dementia charities across the country had united in OneDementiaVoice to call upon the government to grant designated family carers key worker status with the provision of PPE (personal protection equipment) because those care home residents with dementia were suffering physical and mental ill-health, as well as early death, through the deprivation of such regular visits. However, it needs pointing out that many such residents may find it difficult to recognise their visitors (and even staff) both visually and aurally and that care homes have to strike a balance between showing greater compassion and continuing to provide adequate protection to all in their communities. Leading charities have insisted that the government's new social care winter plan should not lead to a blanket lockdown in care homes.

[www.ageuk.org.uk/discover/2020/09/visiting-in-care-homes-where-now](http://www.ageuk.org.uk/discover/2020/09/visiting-in-care-homes-where-now)

Care homes created opportunities for the virus to spread, claims a discursive article in the International section of *The Economist*. It states that a lesson from the pandemic is that most people should be helped in their own homes as they age. In the world's richer

countries nearly half of all deaths from Covid-19 have happened in care and nursing homes, even though less than 1% of people live in them. *'Countries with fewer care homes have had fewer Covid-19 deaths, all else being equal'*.

The biggest study of coronavirus infection rates so far has confirmed the far higher risks faced by care home and health care workers. Conducted by Imperial College London, the study of 120,000 volunteers tested for coronavirus during May found that care workers were 7.7 times more likely than non-keyworkers to test positive, while health care workers were 5.2 times more likely to test positive.

Some care homes still refuse visitors, but the sector welcomes the fact that social care providers have given a guarded welcome to new government guidance on care home visits, which have been resuming where safe. Many, but not all, care homes are now allowing visitors, although decisions will be locally led with directors of public health taking charge of risk assessment processes to determine whether visits are safe to specific care homes in specific communities. Face coverings and social distancing will of course be necessary.

The debate about the usefulness of robots in care homes continued in September. It rated a front page headline: <https://www.theguardian.com/society/2020/sep/07/robots-used-uk-care-homes-help-reduce-loneliness> However, many of us will feel uncomfortable about this – and comments in letters reflected a wish to emphasise the benefits of human care and contact. <https://www.theguardian.com/technology/2020/sep/09/robot-carers-are-an-insult-to-our-most-vulnerable>

### **Legal or quasi-legal issues raised by the pandemic**

Since many care homes in England are still refusing to allow face-to-face visits from relatives, carers' group John's Campaign is seeking a judicial review of government guidance on visits. <https://www.bbc.co.uk/news/uk-54007273>

There has been a storm of protest as new immigration rules exclude social care workers from a new points-based immigration system announced by the government, despite calls for special arrangements for the sector which already has 122,000 vacancies and depends heavily on staff from overseas, especially in care homes. Sector bodies condemned the measures with the National Care Forum (NCF) describing them as the 'wrong policy at the wrong time'.

The basic human rights of people with dementia may have been compromised during the pandemic, researchers have said, with extremely high death rates among older people with the condition. In a global impact study, put together by researchers from the LSE and UCL, data on Covid-19 mortality in people with dementia ranged from 66% of all deaths in Canada to 26% in the UK and 19% in Italy. <https://ltccovid.org/2020/08/19/impact-and-mortality-of-covid-19-on-people-living-with-dementia-cross-country-report/>

### **The importance of music for persons with dementia**

Care homes have been invited to nominate their Top 10 Favourite Songs for a dementia-friendly radio station. M4d Radio is a new venture by the charity Music for Dementia. It wants to play a Top of the Pops-style playlist drawn from nominations made by its care home listeners. It is for M4d's 'Mix' station, which plays music from the 1930s to the 1970s. <https://musicfordementia.org.uk/2020/07/23/care-homes-top-tunes-nomination>

A BBC World Service Music Memories project has been launched with the aim of starting a 'global conversation' to help trigger the memories of people with dementia.

<https://canvas-story.bbcrewind.co.uk/musicanddementiaatthebbc>

Recommendations from an Australian research project outline how music can be used systematically as a first line response to stress and distress behaviours among people with dementia. For the video go to <https://vimeo.com/460125213> and for the Australian research go to <https://musicfordementia.github.io>

### **Other topics**

In July we heard about Active Norfolk's Norfolk Easy Ambles which are tailor-made walking routes of between a half a km and one and a half for people living with dementia and their carers to enjoy in scenic areas of the county which are likely to stimulate conversation and reminiscence. Walking is often seen as one of the most accessible forms of activity, and it can be a significant therapeutic tool when supporting people living with dementia.

[https://www.visitnorthnorfolk.com/inspire/dementia\\_friendly\\_walks\\_north\\_norfolk.aspx](https://www.visitnorthnorfolk.com/inspire/dementia_friendly_walks_north_norfolk.aspx)

In 2017 the Lancet Commission on dementia prevention, intervention and care identified nine salient factors: limited education, hypertension, hearing impairment, depression, smoking, obesity, physical inactivity, diabetes and poor social contact. In July this year they added excessive alcohol consumption, traumatic head injury, and air pollution. They comment: *'Together the 12 modifiable risk factors account for around 40% of worldwide dementias, which consequently could theoretically be prevented or delayed.'*

On August 4 Alzheimer's Society issued a report arising from the recently-held Alzheimer's Association International Conference identifying '5 hopeful takeaways':

1. Coming a step closer to a blood test that can identify p-tau217 which is specific to Alzheimer's.
2. The addition of three further modifiable risk factors (already reported above).
3. The discovery that the drug AXS-05 appears to be effective over 5 weeks in the treatment of agitation caused by dementia; further trials are proceeding.
4. Advances being made (but more required) into ethnic differences in the experience of Alzheimer's.
5. A potential treatment of Alzheimer's through the drug Gantenerumab which appears to reduce the amounts of amyloid in the brain and, along with the amounts of tau, in cerebrospinal fluid.

Publishing the *World Alzheimer's Report* on World Alzheimer's Day, Alzheimer's Disease International (ADI) said governments could set standards for good dementia design, so that the resulting therapeutic benefits were available to people at home, in residential and day care facilities, hospitals and other public buildings and spaces.

[www.alz.co.uk/research/world-report-2020](http://www.alz.co.uk/research/world-report-2020)

A new dementia support project in Wales will see bereavement charity Cruse working in partnership with Alzheimer's Society Cymru. Called *'Supporting loss along the journey with dementia'*, the project will focus on improving access to pre-bereavement support and will assist people diagnosed with dementia and their families in managing and coping with feelings of loss.

A crowdfunding campaign has been launched to raise money so that a playful object shown to help people with advanced dementia can be made commercially available.

[www.crowdfunder.co.uk/hug-by-laugh-1](http://www.crowdfunder.co.uk/hug-by-laugh-1)

Older patients in hospital, including those with dementia, are the focus of a new drive to prevent them from taking potentially harmful medicines. According to The University of East Anglia, half of older people admitted to hospital have been prescribed medicines, which can lead to unpleasant side effects. Research published by the university suggests more of these medicines could be de-prescribed

[www.dropbox.com/s/zd3mw8df40z2xy9/NGT%20paper%20resub%2018.05.2020.docx?dl=0](https://www.dropbox.com/s/zd3mw8df40z2xy9/NGT%20paper%20resub%2018.05.2020.docx?dl=0)

A court ruling in The Hague has confirmed that a person lacking capacity because of dementia, cannot reverse an advanced statement made when they were competent and so may be legally killed by doctors following the correct protocol, even when it may be clear that the person they have become would rather stay alive

<https://www.theguardian.com/world/2020/apr/21/dutch-court-approves-euthanasia-in-cases-of-advanced-dementia>

The scandalous approach in England to the discharge of patients who had Covid-19 to care homes has been deemed legal in court. Ethics is another matter. The phenomenon raises important issue about who is responsible for making individual decisions about what happens to patients: Government? Management? Clinicians?

<https://www.theguardian.com/world/2020/jun/21/releasing-english-hospital-patients-into-care-homes-not-illegal>

~~~~~

## RESEARCH

Being over 55 and living alone with little social contact raises the odds of developing dementia by 30%, a study led by University College London (UCL) scientists has found. They reviewed evidence from 12 studies in seven European and Asian countries, concluding that social isolation could be a greater risk factor for dementia than previously thought.

Similarly, the results of an Alzheimer's Society survey revealed that 80% of those who lived alone had seen no family or friends since March and overall a third of those living with the condition 'felt like giving up'. The survey received responses from 1,831 people affected by dementia.

Research published in the *Journals of Gerontology* on May 26 appeared to show that a gene that predisposes people to Alzheimer's disease may also account partly for figures showing that people with dementia are at significantly higher than average risk of a severe Covid-19 infection. Data from the Office for National Statistics revealed that Alzheimer's disease and dementia is the most common pre-existing condition for people dying of Covid-19 in England and Wales. Researchers found that those with the e4 variant of the APOE gene, associated with a 14-fold increase in Alzheimer's disease risk, and also had more than double the risk of getting a severe Covid-19 infection. The study focused on 500,000 UK Biobank volunteers, aged 48 to 86, who tested positive for covid-19 between March 16 and April 26.

On 8 June *The Daily Telegraph* reported that research at UCL had shown that people who think negatively, especially over long periods, are more likely to develop Alzheimer's, because it is linked to the deposit of harmful proteins in the brain.

A preliminary study of patients hospitalised with Covid -19 published in the *Lancet Psychiatry Journal* on 25 June has found the disease can damage the brain, causing complications such as stroke, inflammation, psychosis and dementia-like symptoms in some severe cases. This points to the need to continue collecting data,

Inflammatory bowel disease (IBD), which includes ulcerative colitis and Crohn's disease, is linked to a more than doubling in the risk of developing dementia, finds research published online in the journal *Gut* in June. What's more, dementia was diagnosed around 7 years earlier in people with IBD than it was in those without this condition, the findings of this large population-based study in Taiwan show. However, the potential influence of lifestyle factors or the prescription of ant-inflammatory drugs were not assessed.

In mid-July the University of Leicester announced the launch of a new research project seeking to understand the long-term and often unexpected effects of Covid-19 in which participants could be monitored for up to 25 years. These would include continuing fatigue, breathlessness, coughs and chest pains, and also serious and potentially fatal brain disorders.

Recent research has told us more about the vulnerability of brains as they age to the effects of raised blood pressure and diabetes; which gives us more to think about and take action about to reduce the incidence of cognitive impairment and dementia:

<https://www.theguardian.com/society/2020/sep/07/high-blood-pressure-diabetes-impair-brain-function-study-memory-thinking>

A most promising recent breakthrough, as reported in *The Guardian* on 6 October, has been the research undertaken in Mexico City which has demonstrated that dust particles in the brain stem of people living in the most polluted areas almost certainly acted as foci for the development of Alzheimer's disease. This is something where action can be taken internationally for the common good. [Air pollution particles in young brains linked to Alzheimer's damage](#)

~~~~~

## **SAD NEWS**

British actress and novelist Jill Gascoine, known for her roles in such TV dramas as *The Gentle Touch* and *The Onedin Line*, died on 29 April at the age of 83 after living with dementia for ten years.

In mid-June the death at 86 was announced of Prague-born psychogeriatrician Tom Arie, a pioneer in modern treatment and support of people with dementia. His work at Goodmayes Hospital in Ilford saw the discharge rate in his first year fall by three-quarters and the death rate by a quarter. He subsequently became founding professor in the department of healthcare at Nottingham University (1977-95). His integrated approach meant that elderly patients with physical and mental conditions could be catered for at a single clinic rather than traipsing from place to place. He found that recruiting and training women doctors with family responsibilities enhanced the care given and that many of those thought to be suffering from dementia turned out to have other treatable conditions such as depression. His great desire was to give patients more independence so that they could live as long as possible with a good quality of life. In retirement he spent ten years working for the Royal Surgical Aid Society, now known as Dementia Carers Count.

The Alzheimer's Society reported the death on 20 June of their Ambassador Barbara Pointon who came to prominence through the showing on ITV in 1999 of the documentary 'Malcolm and Barbara: A Love Story'. Caring for her husband over many years, in 2004 Barbara won a landmark case for NHS funding of those with dementia at home, not just in hospital or nursing homes (Continuing Health Care). Latterly she developed Alzheimer's disease herself.

~~~~~

## NETWORKING

The June newsletter of Edinburgh-based **Faith in Older People** included The following timely letter written on June 1 by **Henry Simmons, Chief Executive of Alzheimer Scotland**: *'Here's a statistic you might not be aware of: around 60 per cent of the people in Scottish care homes are living with dementia. We know so many of them are experiencing high levels of distress due to the current restrictions and changes to their routine. Bear that statistic in mind when you next hear of the number of deaths in care homes across Scotland.*

*Don't think about the raw numbers though - think about the fear, the loneliness, the isolation people with dementia are experiencing during their last moments. Think too of the families kept agonisingly apart from a beloved family member, or not able to mourn or grieve properly.*

*The way coronavirus has affected those in a care setting has been one of the most agonising and difficult themes of this pandemic. The rights and wrongs will be debated for years to come. For now, we must pay tribute to those in the care workforce, who show such bravery, compassion and understanding in the face of conditions which no worker would ever have expected to endure.....*

*In our 2019 Fair Dementia Care report, we highlighted that people with advanced dementia do not receive the healthcare to which they should be entitled. They instead face significant social care charges. We stipulated a clear need for increased access to healthcare professionals and, most importantly, that people with dementia or their families should not be asked to pay for this care. Put simply, their care should be free at the point of delivery, in line with those who have other progressive terminal illnesses. I suspect that many members of the public might not know that, even at the present time, many people with advanced dementia fighting coronavirus in a care home will still have to pay for their care. If we ever needed a reason to stop this inequality, coronavirus is it. Reforming this system must be the bedrock of our recovery, and it should start now.'*

This year's annual conference of **the Society of Gerontology**, 1-3 July, took place online. Of interest was the Flagship Symposium on dementia friendly communities in the Netherlands, Singapore and England, presented by Stefanie Buckler of the Cambridge Institute of Public Health. Amongst their aims are to enable people with dementia to remain actively involved in everyday community activities and to maintain their social networks so that they have a sense of continued belonging. In this sense communities are not necessarily restricted to a geographical locality, but may also include organisations such as a retail business, a national charity or faith community – but in each case the same principles of accessibility, awareness and inclusion should apply.

## Thoughts from Ann Jewell

Back in 2018 we included an introduction to '*Cries from the Heart*', poetry by Ann Jewell (no relative of the Editor) about living with her husband John's dementia. John died on 30 January 2019 aged 89 in the care home where he spent his last days. Ann has sent me the following '*Thoughts*' which are reproduced here, with her permission, in abbreviated form.

At first Ann's mind refused to accept that what was happening to John was not merely part of the ageing syndrome. Gradually, she had to accept that this man, so fluent in speech and expressive in writing, was living with dementia and that the condition would get worse. Highly intelligent, he was good at covering up his lapses of memory and for some time Ann was **able to protect him** from others becoming aware. At first, because of his knowledge of the origin of words, Ann had not wanted the word 'dementia' to be mentioned; he would have equated it with madness. His sight was diminished so that could be cited as a cause for his confusion. The specialist had told him that there were gaps between the cells in his brain, and so at times the thoughts could not jump over the gaps. This he accepted and they went along with that description. Bad sight and gaps in the electric current, these were the protective devices which Ann used with him.

Ann wonders now whether she should have been more open with John as she realised the nature of the disease. But she does not think that he could have coped with the knowledge of the gradual inevitable disintegration which lay ahead. **Guilt**: that was often to be her companion, and even some months after his death, she wondered whether she could have acted differently. But one can only do what seems right at the time.

In the initial stages of the disease, Ann had difficulty in preventing John from doing things of which he was no longer capable. A public speaker, he could no longer formulate thoughts or construct sentences. She wanted him to be remembered at the height of his powers and not as a man diminished and stumbling over words. But once again his sight could be used as a reason for the restraint. But still he longed to do the impossible.

Ann had to learn **coping strategies** as she went along. Any books available then about dementia and carers only accentuated the feelings of guilt. Even the angel Gabriel could not do all that was deemed advisable! When John adopted an eccentric style of dressing, such as wearing three different shirts one on top of the other, Ann learnt **not to interfere** (unless they were going out). He was happy with what he had put on and nothing else mattered. He had always been very confident and would stride ahead of her when out, but now he was hesitant even about entering a room and Ann always had to go first. John also became very possessive and resentful when Ann spoke to or paid attention to anyone else. This also extended to phone calls, so she had to arrange for calls to be taken and made away from home. Ann's full attention had to be on him. As the disease progressed Ann learnt **never to contradict** repressing her own instinct to correct wrong statements. Contradiction only made John angry or caused distress.

As John changed so did Ann. John had always been the one to make **major decisions**, and now that became Ann's responsibility. Such decisions involved becoming John's Legal Guardian and signing a DNR (do not resuscitate) on his behalf. Ann hesitated about both issues - had she the right to decide life and death issues for him? But there was no alternative.

One day, Ann and John had gone out for a meal which had previously been a pleasure. She became very aware that there was **no companionship**. Conversation was impossible and there were words spoken with no communication, **Ann felt very alone**.

When a close family member died, Ann had to decide when to tell John, knowing that he would probably forget. She felt that constantly to repeat the news and explain the connection would prove extremely painful for her. Yet when Ann did eventually tell him, and suggested that they phoned the family, some of the old John became evident. His language temporarily unlocked, he spoke with feeling and sympathy. Ann does not know if John understood to whom, or of whom, he was speaking but thinks he did. **The essential John was still there, although often 'locked in' by the disease**. Somehow the adrenaline kicked in when John was talking to or with his sons, and conversation although limited seemed almost normal. He could not remember their names but asked Ann to write them down so that he could repeat them constantly before she dialled their numbers. Not recalling the names of the rest of the family he would ask, *'How are your loved ones?'* And so, it seems that John by himself had become aware of his dementia and was using strategies for coping.

Hardest to bear was his anger against Ann as the disease progressed. Eventually he went into a care home. Often, he would accuse her of stealing his house and she would respond by saying that she was looking after it for him. **But he could no longer reason** and became angrier. Often Ann felt she was putting her head into the lion's den, not knowing what to expect when she visited. Emotionally battered she often left the room in floods of tears. However, it seems that sometimes, after Ann had left, John was aware that he had upset her and told the carers that he was sorry; but never told Ann herself. Although Ann knew that it was the disease causing his behaviour, so different from previously, he still looked and sounded like John. It was hard to distance herself from the pain and hurt caused by the behaviour of this new John. Yet still, he was essentially still the same. **John was still John**. On one occasion pushed to her limits, Ann vented her frustration and despair by shouting at him - which she bitterly regretted. Ann was not super-human, but it would have been **wiser to have walked away**. John looked at her in bewilderment and together they laughed and cried.

Frequently, even up until his death, he would say that he wanted to be back home and could still wheedle, knowing her vulnerability, but at heart she thinks he knew it was a vain hope as John accepted her excuse that it was too cold, or the weather was not right. On one dreadful day Ann found John weeping bitterly assuming that Ann did not want him back because he was so awful and that she did not love him anymore. All she could do was to weep with him but yet still could not fulfil his desire - to be back home. When it was fine Ann did bring him back to the house, but he was always anxious to return to the care home for his meal. That was part of **the routine** which had become important to him.

During the last few months of his life some of the anger and frustration caused by the disease abated and a part of the old loving John emerged. He expressed his gratitude to Ann when she left him and seemed to have found a degree of contentment; yet still the same mantra - 'I want to come back home'.

When John died Ann was once again consumed by guilt. Although in her mind she knew that it had been impossible, in her heart she wondered if, after all, he could have remained at home under her care as he had wished. Although overwhelmed by sorrow she could not wish him back. She grieved for the old John whom she had lost some years before but could not wish him back to this changed mode of life, realising that only deterioration

would have lain ahead. **There is a worse thing than death.** The John whom she had known and loved had already gone, through this disease. As it progressed, Ann saw it as a **living death.** For John, **death came as a friend,** a release Ann hopes into a better life,

Ann ends by quoting one of her own poems:

*Months of restriction and frustration lie behind,  
Although transformed vague memories still quiver,  
But now that I have found my wings  
I know that I can fly,  
Soaring into an unknown destiny.*

*Ann Jewell (as told to the Editor)*

### **Reflections of an Anna Chaplain on the privilege of being a volunteer in a care home whose residents have advanced dementia**

I am writing this article on 23 September 2020, which as a BBC news reporter reminded us is exactly six months following the major Covid-19 national lockdown. This means that it is six months since I have been able to do my voluntary work in my local care home. During this time I have kept in touch and only yesterday spoke with the deputy manager, who was delighted to tell me that they are still Covid free. All through this difficult period committed staff have managed effective prevention measures.

I started my voluntary role on 1 May 2018. I believe God calls us to do work by many different signs and prompts, and in my case, it was because my long-term college friend had Alzheimer's. I felt that maybe I could contribute but was unsure as to how. In discussion with staff at the home it was suggested that to read to individual residents might be helpful. However, it soon became apparent that simply one to one interactions were what individuals needed.

My main work has always been with individual residents, but inevitably I also interact with families. Gudrun was the wife of resident David. She always told me she felt guilty, as she was no longer able to care for him at home, because when he fell over, she could not lift him. I always reassured her that she had taken the right decision, as she was still giving him warm, loving care as she visited so regularly. Our relationship only lasted a few months until David died, but I did see her two or three months after his death when we were both shopping locally and we had a lovely conversation about the amazing care he had been given by the staff.

One day I had a delightful surprise whilst I was talking to Nora when her family arrived for a visit. As usual I greeted them and told Nora I would come to see her again next week. I moved on to another resident, but as I did so, Nora's daughter asked me if I was Mrs Simmons (I simply wear a large badge with EILEEN on it), I said yes and she was pleased to reintroduce herself to me as the mother of youngsters from my school over twenty years ago!

I have so much missed my voluntary work over this last six months. As an Anna Chaplain I am committed to working with Older People, so currently I work with Age Concern doing telephone befriending with individuals, some of whom have medical conditions, which means they are high risk. This work is interesting but my heart aches to return to my care home. One of my residents is normally totally silent and does not engage at all with other residents or staff. Ivy loved her cat, and I would talk about 'puss' and very occasionally

she would smile at me and said, *'It's very nice to see you'* and then went silent again. In the two years she normally has seemed peaceful and tranquil. Simply to be with her seems to be helpful. One day she looked at me and said, *'We do not see you very often these days'*.

On reflection the benefit I seem to offer is that I have time. I can spend as long as is needed with an individual. Once Nancy became very agitated and cross with a member of staff, who tried to pacify her by saying that when she had been moved she could talk to Eileen. I did join her and was able to calm her as I was not making any demands. She really enjoyed talking about a whole range of personal issues, but over the two years there has been a marked deterioration in her coherence.

Most residents do not remember me from week to week, but one seemed to remember me right up to her death. She always said *'Hello dear'* as soon as she saw me, and I would always confirm that I would spend time with her. Most weeks she would ask me what I thought about the awful storm we had during the night and of how she came downstairs into the lounge, as she was unable to sleep through it. The same story was repeated of how police (or soldiers) arrived and stamped on her hands and broke her fingers. She also believed that she owned the care home. I simply listen and show interest. I think my Samaritan training from long ago helped.

Every interaction is different, a precious time between two individuals and I find it a real privilege to be able to make the visits. Currently I am not able to go but look forward to returning.

*Eileen Simmons*

Anna Chaplain

Postscript: All names have been changed in this article. I always seek permission of the Care Home Manager before offering anything for publication.