

Notes from a Christians on Ageing Conference Call

Supporting the carers of people with dementia

This was a Zoom conference held on **17 November 2020**. We were: Julia Burton-Jones who led the webinar, Albert Jewell who made a presentation, Janet Hopewell, Julia Clements, John Portman, Tina English, Kathryn Lord, Marion Shoard, Eileen Simmonds, Helen Coates and David Jolley (host and scribe)

People were welcomed and invited to say a few words about themselves and their work.

Julia B-J explained that she has been interested and involved with carers for more than 30 years. She studied Social Policy at Bristol University and continued study and research at Cambridge University.

- An early and formative project was 'Out of sight, out of mind' – a study of family carers.
- With Dementia UK in its previous incarnation she developed a scheme where family carers help train professional who are involved in the care of people with dementia. 'Skills for Care' is available
- <https://www.skillsforcare.org.uk/Documents/Topics/Dementia/Dementia-and-carers-workers-resources.pdf>
- She has been involved with Admiral Nurses – a main product of Dementia UK <https://www.dementiauk.org/get-support/admiral-nursing/>
- She currently works in and through churches in Rochester and is an Anna Chaplain. She provides spiritual care for older people – in lockdown this has to be mainly over the telephone.
- She leads special days – with poems, hand massage and a Dementia Friendly worship service

Asking those assembled what their experience has been like during lockdown, we heard that

- much use is being made of **telephone contact** for support and information. It is not the same as the 'in-the-flesh' experiences of care that people have been used to; not the same but probably better than nothing.
- There are many long days – day after day without the punctuation and relief of activities such as day care
- we heard of the very sad funeral of a woman who had cared for her husband with dementia for many years, but just could not go on any longer when lockdown took away her support
- Interviews with 42 informal carers of people with dementia and 8 individuals living with dementia by Liverpool University confirmed that both groups are finding the loss of support services stressful and distressing: feelings of loss of control, uncertainty and having to find another way of living for the time-being <https://www.tandfonline.com/doi/full/10.1080/13607863.2020.1822292>

In all situations, 'Social distancing' feels uncomfortable and is alien to many who are natural carers.

We asked: What are the main needs of carers and can we meet them in this situation?

Albert Jewell spoke to the **research** he had led with others from *Christians on Ageing* recently:

The 2016 research, in which COA was much involved, investigated the **burden borne by Christian family carers of loved-ones with dementia**, either at that time or in the previous 5 years, and led to the publication of two articles:

- one on **the faith of such carers** (how it helped & how it was impacted by the burden of care),
- the other on what we called '**the loneliness of the long-distance carer**' which addressed their sense of isolation.

We managed to recruit 53 such carers who completed a questionnaire of 12 questions with plenty of extra space to expand their replies - which many did at considerable length! They came from a whole variety of Christian denominations, some of whom had cared for their loved ones for over 20 years. It produced a wealth of material based upon answering a questionnaire of 12 basic questions plus plenty of space for added comments which was very well used!

The **main findings** briefly were:

- that the participants' faith had been challenged but in some cases had been deepened rather than reduced. Sadly we were not able to access any whose faith might have been destroyed by the whole experience & were no longer church-connected.
- the support from their faith community had been appreciated but they mostly felt that churches should become more dementia-aware and dementia-friendly (something that **does** seem slowly to be happening).
- to expand: they mostly doubted that their churches had an adequate idea of the stresses that family carers were under, especially where as so often it was a case of a single carer trying to cope long-term.
- a significant number 'confessed' to the toll taking the form of emotional responses they experienced such as **frustration/anger** (with the person they were caring for or with the lack of support received), deep **grief** (both at the sense of loss before the death of their loved-one or after their eventual bereavement), **guilt** at what they regarded as their lapses in caring, and **depression** because it brought them very low. All of these have been noted in other studies that have not been restricted to Christian carers. But Christian carers are far from exempt from them!

In the current issue of our *Dementia Newsletter*, which I edit, I have included a recently received letter from Anne Jewell (nom de plume & no relative!) which expresses all of the above very poignantly in the aftermath of the death with dementia at the turn of the year (just before lockdown) of her husband John for whom she was the primary carer for several years until he went into a care home. She writes of painfully learning not to contradict John & provoke his anger, of feeling very alone because there was no longer any companionship in their relationship, of feeling at times emotionally battered, and of her intense guilt.

And finally of course we need to take to heart the frustration, sorrow and anger in families who have not been able to visit their loved ones in care homes during recent months which is particularly distressing in the case of residents with dementia who simply cannot understand what is happening and why and makes them fearful that their relative may well die feeling abandoned by their family.

Contact Albert Jewell on aji633@btinternet.com if you would like to have copies of the two articles

<https://www.growingoldgracefully.org.uk/dementia-the-forgotten-heroes-churchgoing-carers-speak-of-their-long-and-lonely-road/>

We heard from **Tina English** about new initiatives for carers through Embracing Age:

- <https://www.embracingage.org.uk/>
- We heard about **Carers Christian Fellowship** – which was helpful to many, but has ceased to function after 25 years – leaving a gap in provision <http://www.careforcarers.org.uk/about-us-2>
- We were recommended a recently published book on worship and spirituality with people living with dementia: **God in Fragments**:
<https://www.chpublishing.co.uk/books/9780715123676/god-in-fragments>

Kathryn Lord shared information about work she is involved with in Sheffield:

Kathryn shared information about work she is involved with in Sheffield: Stories for the Soul <https://www.storiesforthesoul.org/our-church-at-home> Stemming from early activities including Godly Play, she and Carrie Twist In association with Professor Claire Craig of Sheffield Hallam University are developing freely downloadable worship resources for use by activity organisers in care homes and other situations. There will be 24 themes (e.g. hope, friendship, loss, as well as the religious festivals) and will include a short, filmed story, links to hymns and free downloadable resources to explore each theme. Short videos with suggestions of how to use the resources will be included. The resources will be dementia friendly and designed to be used in groups in a care home as well as intergenerationally and in a family home context. They will be spiritually nurturing and aim to be inclusive of people without a Christian faith.

Stemming from early activities including Godly Play, she and the team find the situation for people with dementia and their carers was heart-breaking before Covid 19 but is now much worse.

We were reminded that **Anna Chaplains** have produced booklets at modest cost <https://www.brffonline.org.uk/collections/carers-guides>

People are creating 'Our church at home'

- We heard that even before lockdown, some carers found themselves unable to get to church because of their unbroken responsibilities. When released from these responsibilities, it is not easy to re-engage – People need to be supported throughout – and helped to return if and when this feels right
- We heard of the devotion shown by family carers, but the great toll caring can take.
- We heard of relief at death.
- We heard of feelings of guilt when a person with dementia is placed in a care home.

Pastoral groups have had to modify how they provide support – often for now by telephone.

- The add-ons available through **day care are much missed**.
- We heard that while the Alzheimer's Society has ceased all its day care and other support activities, **Age UK** in some places declares its activities to be 'essential' and so they have continued.
- While carers are glad for respite of this sort, some will not use it during lockdown/the Covid Crisis for fear of the infection
- Peer support meetings on-line can be successful. Some families have set up their own Zoom meetings.
- There are mentions of Dementia Café online. It is not easy to make singing on line work for people with dementia – but some will say it can be done
<https://www.alzheimerswiltshire.org.uk/virtual-music-and-movement>

There is a general learning point that activity which works well in the flesh has to be thought through and adapted if it is to work 'on screen'

There are people who **do not have the internet** – and there are people who do not want it or other modern means of communication. They are to be respected and ways found to keep in touch with them and provide for their needs in ways which they are comfortable and confident with.

Marion Shoard agreed that **digital means to replace pre-Covid face-to-face encounters and church services provided limited benefit** for people who, by choice or circumstance, are digitally excluded and also people with dementia, especially the many who are also blind or partially sighted.

- She said that those caring for people with dementia are hit particularly hard by Covid partly because so many day services have been suspended but also because they **dare not place their loved one in a care home lest they be unable to visit them there.**
- She suggested that one way in which church people might help the carers of people with dementia to cope was to offer to form a household bubble with them. This would enable the two households to meet indoors or out and might involve the church volunteer sitting with the person with dementia so the carer could take a break and/or helping in many different practical ways; they might even stay overnight.
<https://www.gov.uk/guidance/new-national-restrictions-from-5-november>
<https://www.gov.uk/guidance/making-a-support-bubble-with-another-householdn> “

We are aware that some people who were regulars at support groups have died during these weeks. There is a sense of great loss – and an emptiness it is difficult to deal with.

BBC 4 'Call You and Yours' has run sessions on the situation for carers in lockdown
<https://www.bbc.co.uk/programmes/m000pfg4>

We heard that at present it can be very **difficult to become registered as a volunteer** because so many of the roles essential for recruitment have been ended or furloughed. But, dementia care relies on volunteers to fill gaps which professionals cannot cover.

This was a fascinating, in depth exploration of the topic – providing information, time and space to share personal doubts and difficulties, and with many ideas and inspirations which will be followed up.

This is the last in this second series of Conference Calls. *Christians on Ageing* intends to run further series through 2021.