

When actions are louder than words 14 MAY 2021

Robin Thomson suggests practical ways in which churches and individuals can support those suffering from dementia, and their care-givers

IT IS easy to feel powerless or uncomfortable in the face of Alzheimer's, or other forms of dementia, which directly affect about two million people in the UK today (about 850,000 people are living with dementia; 700,000 families are providing care). Although attitudes are changing, fear and incomprehension are still common responses. When my wife, Shoko, was diagnosed with Alzheimer's in 2012, we had very little idea of what lay ahead, or how to respond. Later, as the disease took hold, we learned the hard way. Shoko's personality changed, and she lost her capacity in many areas. Despite this, her affection remained constant. She died of heart failure in 2018.



Each person's experience of dementia is different, but there are common questions. How can we learn to respond with love and understanding? How does the gospel affect our understanding? This was the theme of a recent seminar, going back to basic principles: "People living with dementia are persons. They are looking for a sense of attachment, belonging, and identity. They need to feel comfort and inclusion." Feelings continue when cognitive ability may have declined: pleasure at being visited, anxiety in new surroundings, or sadness when somebody near them seems worried or impatient; so relationships are most important. And family, friends, churches, and community groups have a vital part to play in providing love, friendship, and support, for the caregivers as well as the sufferers. Our local church supported us well. Sunday morning, 9.30 a.m., was a highlight of the week. Shoko might be struggling to find her glasses, looking through her handbag, trying to open a hymn book or Bible, not sure which was right; sometimes she seemed sleepy. But she was happy to be there, and would greet our friends with a smile, whether she knew who they were or not. People were warm, greeting us both with affection, and talking to Shoko. It was an oasis for me, as well: to join in the singing and prayers, to hear the Bible being taught, to be reassured by the concern of friends. They truly demonstrated the gospel and the support of a loving community — at a time when my faith was severely challenged.

AT THE same time, I could see that many felt ill-equipped and unsure how to relate, or what help they could offer — afraid, perhaps, of making mistakes. Living with dementia and caring for a person living with dementia are strange situations. The disease may come in stages: sometimes it's not noticeable at all. There may still be a certain stigma to acknowledging it openly. At what point do we speak about it? There are no rules; like any relationship, it needs respect and sensitivity. Similarly, giving practical help doesn't always seem straightforward. What can we offer, and when? People may be reluctant to ask for help, or even to acknowledge their situation. But we can, I believe, be more open and intentional. When people recognised our situation, and asked how we were (and meant it), I always found it encouraging. So, church leaders, individual members, friends — all need to take the initiative. Don't wait to be asked, but find out what will be helpful — from food to financial matters, health issues, going for a walk, transport, and more. One of our friends turned up with a complete meal, which he left with us. It isn't always easy. You might find your friend changed, perhaps not recognising you; or, even if they do, not engaging very much that day. If that is all you see, you may wonder whether it is worthwhile. But it is. It brings pleasure at the time, even if soon forgotten; and, crucially, it supports care-givers, too. They can feel isolated. Some may be squeezed between an older parent to visit and the younger generation at home. "I feel so alone," a friend wrote recently. For more than a year, much of what we can do has been severely restricted. It's hard to over-estimate the devastation for those living with dementia and for their care-givers. The loss of sustaining relationships for people in care homes has been widely reported — even for those at home or with family, the restrictions on normal social interaction have had severe effects.

Some actions that will almost certainly be welcome (with or without Covid-19):

- organising a **meal rota**, as appropriate.
- **Visiting** (when rules permit). This could be to spend time with either the person with dementia, or the care-giver, which would be welcome. Or it could be to **release the care-giver** to do something else, or go out. It's common for the person living with dementia to be so dependent that the care-giver has little or no time for themselves. Giving them that time could be like gold.
- With the person living with dementia: **be yourself and relate normally**. You may need to take more initiative to direct the conversation or activity — for example, games, photos, songs on an iPad, or singing together. Music is powerful.
- When visiting isn't possible, it might be a **phone call, letter, email, or video call**. For some, this will only reach the care-giver — but that's very worthwhile. A friend used to phone me regularly, just to ask how things were going.
- Care-givers have another important need: **somebody to talk to in confidence**, to express emotions to, and pray with. I met our vicar every three weeks, and it was a lifeline.
- Some appreciate **help to continue attending a group** they belong to, perhaps by offering transport. Zoom may be a poor substitute, but can work for some.
- Some churches have **support groups** for people living with dementia and care-givers. Some offer a simple monthly **worship service**. In the seminar, we heard about the Barnabas Dementia Support Group at All Saints', Crowborough, in East Sussex. During lockdown, they kept in touch with regular phone calls (for more information, contact the team leaders via margaret@margaretgould.uk).
- **Seminars** can help raise awareness within the church, and link people to local community resources.

The most valuable thing you can do ~ I LEARNED — rather late in the day — that the most valuable thing was the way I related to Shoko. “Your body language is more important than what you say,” our daughter told me many times, long before I understood it myself.

It was true. If the tone of my voice was impatient, or if I hustled Shoko to sit down, or get up, or go out, she found it distressing: “Why are you so cross with me?” If I spoke softly, or held out an encouraging hand, the rewarding smile warmed me more than I deserved.

Dementia can be fearsome and mysterious. But we learn not to be afraid. The persons affected are still persons, and we go on relating with love and attention.

Robin Thomson is the author of Living with Alzheimer's: A love story, published by Instant Apostle at £8.99 (Church Times Bookshop £8.09).

FURTHER RESOURCES Some of the **books** I found that offer practical advice:

Live and Laugh with Dementia: The essential guide to maximising quality of life, by Lee-Fay Low (Empower, 2018).

Dementia: A positive response — hope, help and humour on the journey, by William Cutting (Onwards and Upwards, 2018).

Communicating Across Dementia: How to talk, listen, provide stimulation and give comfort, by Stephen Miller (Robinson, 2015)

Finding Grace in the Face of Dementia — 'Experiencing dementia: honouring God', by John M. D. Dunlop (Crossway Books, 2017).

Websites: faithinlaterlife.org annachaplaincy.org.uk dementiafriendlychurch.org.uk