

# Running the final lap, Keswick Convention 2023

## Session 3. Forgetting: the challenge of dementia

".....So we do not lose heart. Though our outer self is wasting away, our inner self is being renewed day by day. For our light momentary affliction is preparing for us an eternal weight of glory beyond all comparison as we look not to the things that are seen but to the things that are unseen, For the things that are seen are transient, but the things that are unseen are eternal." 2 Corinthians 4:16-18

Dementia has replaced cancer as the most feared illness for many people. For some Christian believers it seems to have a particular horror.

### Medical perspective

In 2021 944,000 people were living with dementia in the UK. This is estimated to rise to 1.6 million in 2050.

One in two of us will be affected by dementia in our lifetime. Either by caring for someone with the condition, developing it ourselves, or both.

Dementia is an overall term for a number of different medical conditions, each with different patterns of impairment. A central feature is memory impairment.

A helpful image is that of a door gradually shutting on a store cupboard. At first I can reach in partially and with difficulty. Then I can only see through a crack. Then the door seems to be largely shut.

But the emotional tone of memories remain, long after the factual content has gone.

Battering against the closed door of irretrievable memories feels like a form of emotional abuse. Being made to feel stupid, feeling a failure, shame. Being treated like a child. Feeling lost and at sea.

Although dementia starts as a pathological process within the brain it has widespread consequences: personal, relational and spiritual.

We must always consider the complex interplay between the individual and other people: family, friends, carers, pastoral workers and professionals.

*"I think therefore I am"* implies *"I remember therefore I am"*. Memory is essential to my identity.

But who am I if I can no longer remember...?

### Spiritual perspective

Dementia seems threatening, because it challenges our common understanding of what it means to be a human person, of the importance of knowing and remembering my personal story. But in biblical understanding, my identity is held secure in the knowledge and the providential purposes of God.

My human identity, my significance, my story is held in the unchangeable reality of God himself. Through God's grace, there is a stability and security whatever events may befall. Even if my brain starts to malfunction, and I become confused, disorientated and lose my memories, I will still be me, a unique person, with a unique story, known and loved by others, and ultimately safe in the loving knowledge of God himself.

My personhood is secure in the eternal knowledge and covenant love of God himself. I will always be "me". I will always be worth what God thinks of me. I am held secure in the unchangeable reality of God and his purposes, which stretch from "before the foundation of the world" to the future "ages of the ages".

Never underestimate the deep and hidden work of the Spirit that may be taking place in the believer with dementia.

At the same time as carers we are also called to recognise the lostness, the distress, the confusion, the anxiety, the anger and the broken relationships which dementia can cause.

### Spiritual care of people with dementia

Spiritual care includes:

- Showing solidarity
- Reinforcing personal identity
- Bringing hope



When I am forgetting who I am, I need you to remind me who I am, to comfort me and remind me what has been important to me. To "re-member" for me.

When I can't pray for myself, I need to know that you will pray for me, read the Scriptures, sing Christian songs for me, and lead me in worship. I need you to reassure me that I am safe, that you will always love me and that you won't abandon me.

People with dementia often retain a capacity for emotional intuition. They are sensitive to qualities of trustworthiness, love, warmth, respect and genuine care.

By 'just being there' with the other person we can express emotional intimacy and presence. Prayerful, loving, gentle attention, including attentive listening to body language.

Most people with dementia are hungry for physical contact. But it is important to respect physical boundaries and ask permission. Holding or stroking hands can be especially significant.

Listening attentively: "I don't understand" rather than "You are not making sense"

Try to respond to the emotional significance of the words by reading the body language.  
We validate the experience of another person by accepting it's emotional reality, power and "subjective truth".

"In general it is good to affirm the reality of the person's feelings but not to do this in ways that compromise consensus reality too much." Joanna Collicutt

### **Actions speak louder than words: the importance of ritual.**

Formal prayers and blessings  
Hymns and spiritual music  
Significant objects  
Inclusive church services

Suffering is not a question which demands an answer, it is not a problem which demands a solution... it's a mystery which demands a presence.

The impact of dementia on loved-ones and carers  
The emotional and spiritual impact on a spouse and on children can be devastating, and yet it seems that this is often ignored or 'airbrushed out'.

Although we know in theory that the other person has lost their cognitive capacities, we can find ourselves drawn into repeated arguments and conflict; we may have feelings of frustration, anger, hurt, guilt, helplessness or a deep sense of failure.

"People with dementia can find your most vulnerable part and poke at it until you yourself feel unravelled." Dasha Kiper, *Travellers to Unimaginable Lands*

"Remember that there are things in life which cannot be fixed by you, or anyone else. Dare to believe that simply being present with people in the valley of the shadow of death really does make a difference." Joanna Collicutt

"We shouldn't try to care by ourselves. Care is not an endurance test. We should, whenever possible, care together with others. It is the community of care that reminds the other person of his or her belovedness." Henri Nouwen

"We are not being asked to work miracles, unless the miracle is that we are there." Ian Knox

When we care for a person with dementia with genuine respect, sacrificial love and compassion, we are pointing towards the future. We are bearing witness to Christian hope.  
We are saying 'This is not the end of the story – there's more going on here than you can see'.

### **Some resources**

*Thinking of You: the spiritual care of people with dementia.* Joanna Collicutt, BRF

*Dementia: Living in the memories of God.* John Swinton, SCM Press  
*Dementia from the inside:* Jennifer Bute and Louise Morse,  
*Faith in Later Life: resource hub.* [faithinlaterlife.org/resource-hub/](http://faithinlaterlife.org/resource-hub/)

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