

## Session 2: SUMMARY

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### Understanding Dementia

Dementia is a set of symptoms caused by disease of the brain.

There are many types of dementia, the most common being Alzheimer's disease and Vascular dementia. Other types include Levy Bodies, Fronto-Temporal and dementias linked with Parkinson's disease and other neurological conditions.

Common symptoms include memory loss, perception difficulties, issues with sequencing and co-ordination, personality changes – depending on what parts of the brain have been affected.

However, every individual's journey with dementia will be different, depending on their social circumstances, the cause of the dementia and the different parts of the brain that have been affected.

Dementia is a progressive disease, meaning that it will get worse and the symptoms will change as the function of the brain diminishes.

We can't cure dementia but we can treat the person living with it. Apart from medications which can be helpful to slow down the disease for some, the most important treatment is our response of love and respect. The person living with dementia, like all of us, needs to experience love, expressed through

- being made comfortable
- a sense of identity
- a sense of attachment
- a feeling of inclusion in conversations and activities
- the experience of being occupied as purposefully as possible

Dr Tom Kitwood described this as 'the flower of love'. [5]

#### Further information

You will find several books explaining dementia listed in the appendices at the end. There are also excellent videos on some of the websites listed there.

Tina English's book is an introduction to work with older people in general. The chapter on Dementia gives a clear and comprehensive overview in just 20 pages.

Tina English: A Great Place to Grow Old, London, Darton, Longman & Todd, 2021

## Session 2: SUMMARY CONTINUED

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### B. The Challenge of Caregiving

Caregiving is often an unexpected curve ball that life throws people, and it can be exhausting, bewildering and isolating. Carers can feel unprepared, inadequate, guilty, frustrated, disappointed, bereaved, lonely, and emotionally and physically spent.

The experience of caregiving is unique to every individual and the challenges of caregiving are likely to change as dementia progresses.

Caring for a loved one with dementia can create:

- **Financial challenges** – e.g. increased costs of laundry, paid carer support, home adaptations
- **Emotional challenges** – e.g. the person with dementia stops recognising the carer, or gets angry and blames the carer, feelings of loss and bewilderment, carers can feel anxious about what will happen to their loved one if something happens to them
- **Physical challenges** - as dementia progresses a person's mobility might be impacted and they might need help with washing, dressing, getting out of bed, pushing a wheelchair, etc. With limited free time carers may neglect their own health and wellbeing
- **Relational challenges** – Carers looking after a parent may feel like they are taking on a parental role. Relationships between husband and wives can change as dementia progresses and spouses become carers
- **Spiritual challenges** – Carers may struggle to connect with their church if they find it difficult to get to church meetings, leaving them isolated from their church community. They may be questioning God as to why. If church communities are not equipped to come alongside carers and those living with dementia, the carer may feel abandoned by the church. Many carers will draw comfort and strength from their faith and hope for the future.
- **Transitions** can also be challenging, such as when a loved one moves into a care home, or when the loved one dies. Caregivers need support through these challenges as their role and identity as a carer will be shaken, as well as the huge emotional toll of loss and bereavement.

There are around 540,000 carers of people with dementia in England.

Stats from the State of Caring Survey 2021 [6] (includes all caregivers, not just those looking after someone with dementia):

## Session 2: SUMMARY CONTINUED

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- 1 in 8 adults are carers (rose to 1 in 4 during pandemic)
- 8 out of 10 feel lonely or isolated (rose to 91% in 2021, with 34% saying they often or always felt lonely)
- 30% say mental health is bad or very bad
- 25% say physical health is bad or very bad
- 31% struggling to make ends meet financially

Let's not forget that caring for a loved one with dementia can be a positive experience too, alongside all the challenges.

It's important to help carers to provide meaning to their daily life. There are many ways to realise this: 'I'm doing this because I love her', 'I have a significant contribution' and so on. One of the ways is to realise that this is a calling, with all its implications.

Robin Thomson wrote this about his experience:

*"A book I read [John Dunlop] had a whole chapter on the challenges for the primary caregiver. As I read it I ticked off each one. The demands were physical, mental, social, emotional and spiritual. I realised that he understood our situation. But then how should I respond in order to keep going? He made it clear that the caregivers' role is a calling to serve and to love. There are different ways to express this, depending on the situation, whether the loved one continues at home or not, and other factors.*

Another friend wrote, around the same time:

*"It amazes me how the Lord invites us to love more and more deeply in ways we would not have thought of when we were younger ... Well done. You and Shoko are in my prayers."*

*I didn't really want to accept this 'invitation'. It was too challenging. But ultimately it was also moving and encouraging, to deny oneself, take up the cross and follow Jesus (Mark 8:34).*

*It was a calling and there was a purpose. Perhaps I would find out more about what that purpose might be as time went on."*

## *Session 2:* SUMMARY CONTINUED

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An experienced caregiver has made this comment:

“Caring for a loved one with dementia is one of the most difficult challenges we may face, and it can be overwhelming. Before being sucked dry, it may be wise to review the situation, to see what you may let go of and what you should maintain control of, to find others who are capable and willing to take over.”

*Letting go and finding others to help may not be easy for caregivers to do. So it could be one of the important areas in which we can support them.*

*We'll explore further how we could do that in Session 4. For now, having an understanding of the challenges that caregivers face will help us develop empathy.*