

Why Christians should learn about dementia

**Book Review: *Dementia from the Inside: A Doctor's Personal Journey of Hope*
Dr Jennifer Bute with Louise Morse, SPCK, 2018, 116pp, £9.18 (Kindle £6.99)**

With so much to learn and so little time, selecting helpful, informative and educational literature that doesn't waste one's time is important. Reading Dr. Jennifer Bute's *Dementia from the Inside* would be time well spent as an introduction and help for pastors, church officers and members alike.

Dementia is common

The sad reality is that dementia is very common. In 2015 around 850,000 people in the United Kingdom were struggling with the condition and this is expected to increase to over one million by 2025 and could be over two million by 2051.

Dementia is complex and often misunderstood

Alzheimer's is a form of dementia, but not everyone with dementia has Alzheimer's. While Alzheimer's – which deteriorates and shrinks the brain – accounts for around 60% of all cases, there are said to be over a hundred other causes. Dr. Bute gives an overview of the most common forms and how they affect the individual, including:

Vascular dementia – from a lack of oxygen to the brain caused by a stroke and other brain damage;

Lewy Body dementia – often accompanied by severe hallucinations, immobility and lack of balance;

Pick's disease (frontotemporal dementia) – a much rarer form that causes speech difficulties, behavioural problems and personality changes;

Parkinson's dementia – this is a direct progression from Parkinson's disease and is distinct from Lewy Body dementia which often accompanies Parkinson's;

Korsakoff's syndrome – resulting from a thiamine deficiency due to heavy alcohol intake.

Certainly, the last thing dementia sufferers need is DIY doctors giving speculative diagnoses about what form of the disease may be affecting them. But knowing there are different varieties of dementia, with different symptoms, can increase appreciation of its complexity and how it affects each individual in different ways.

Dementia strugglers need appropriate care and understanding

In the first two chapters author Jennifer Bute tells her own story and how she came to be diagnosed with early-onset dementia. This autobiographical introduction helps the reader to understand the person behind the condition and the deep peace and hope she has through her faith in Jesus Christ. I was drawn into Dr. Bute's account; her easy-to-read style provides far more practical understanding of her condition than a clinical dissertation ever could. As she recounts the highs and lows of her life, alongside her husband Stanley and their family, and I found myself sharing in both the frustrations and joys of her experience.

Particularly sad to me is Dr. Bute's account of the unhelpful lack of compassion and understanding she has sometimes received since her diagnosis. Some examples of poor pastoral care show that many Christians, even those in leadership roles, don't have much of a clue how to care for the elderly and others struggling with dementia. In one instance a pastoral care team member questioned whether it was worth visiting someone with dementia as she might not remember the visit or the visitor! In another incident, following her husband's death, Dr. Bute relates how she warned her church leaders about the possibility of her having a public meltdown at some point (a common side-effect of dementia often due to confusion, too much going on in the immediate environment, and being among unfamiliar people). One response was, 'Well don't come to church then', which displayed a shocking lack of compassion and empathy.

Sadly, this lack of consistent and compassionate care for the elderly and those suffering from dementia is more widespread in evangelical churches than we would like to think. I remember one occasion when a student worker from a large, well-known, centre-city evangelical Anglican church responded to a testimony I gave of my personal work with the elderly with unbridled incredulity: 'But you're a cool guy! Why are you spending so much time hanging out with old people? You should spend more time with students.' Are not the elderly and dementia strugglers worthy of our care and attention too?

How churches can be more accessible to dementia strugglers

Reading *Dementia from the Inside*, should challenge and stimulate both pastoral workers and everyday Christians to think of ways in which better care and understanding of those with dementia can be engendered. Some initial points of application for pastoral teams include:

- Consider providing or publicising seminars on old age and dementia for everyone

Practical teaching on the potential consequences of old age will both prepare us all for the challenges we will likely face one day if we live that long, and help church communities better appreciate the struggles some currently face – including dementia – and the biblical hope that can be had in the midst of such difficulties.

- Create an atmosphere of welcome and understanding in church

Exclusion is not an option! A care home should not be the first option to be considered when thinking of how to provide for church members with dementia. Ideally, provision should be made to enable the sufferer to continue to take part for as long as they are able in normal church events. Dr. Bute gives three helpful reminders to this end:

1. *There is always a reason why a person is behaving in a particular way*
2. *When facts are forgotten, feelings remain*
3. *Familiar patterns of behaviour continue*

So, when a sufferer's confusion is evident in a public setting, conversation should be steered away from direct questions that require memory, patient reassurance should be given, and a gentle removing of the person from the source of the distress (without drawing attention to the situation) are steps that can be taken to limit embarrassment and make ongoing community involvement more sustainable.

Cultivate relationships with the elderly and dementia strugglers

Dr. Bute helpfully highlights that the ability to receive and give love never disappears, regardless of the stage of dementia. This is why developing relationships and conversations with dementia strugglers is so crucial to the individual's well-being. Coordinating means of spiritual, mental and emotional support through befriending, providing transport, playing games, and Bible study is Christ-like and immensely worthwhile.

Conclusion

Dementia from the Inside is a must read for any pastoral worker who desires to helpfully minister to those struggling with the disease. This is not an academic book and would be very useful to family members and friends of someone recently diagnosed. It could potentially be a comfort and help to sufferers as well. I am sure that Dr. Bute's volume, along with other resources she has published, will continue to be an aid and blessing to many for years to come.

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