

Memory Matters

Julia Burton-Jones has recently been appointed by The Diocese of Rochester as its dementia specialist project officer.

Can The Devil Take Your Memory?



Pop sensation Ed Sheeran sings about Alzheimer's in his heart-breakingly moving song, Afire Love. In the lyrics, his father explains that it's not the grandfather's fault that he can't remember names and faces. The lyrics talk about the devil taking his grandfather's memory and later, the devil taking his grandfather's breath away and the funeral that follows.

A hugely talented lyricist, it's not surprising that Ed Sheeran has found a form of words that encapsulate the emotions and challenges that affect a person with dementia. What is perhaps more surprising is that the subject matter has found resonance and acceptance in 2015 pop culture, when as little as maybe 15 years ago, dementia wasn't something openly discussed. Ed Sheeran is to be congratulated for helping to bring something so painful into contemporary consciousness and making dementia something that young people can talk about.

Julia Burton-Jones is dementia specialist project officer for the Diocese of Rochester. She said, "My interest

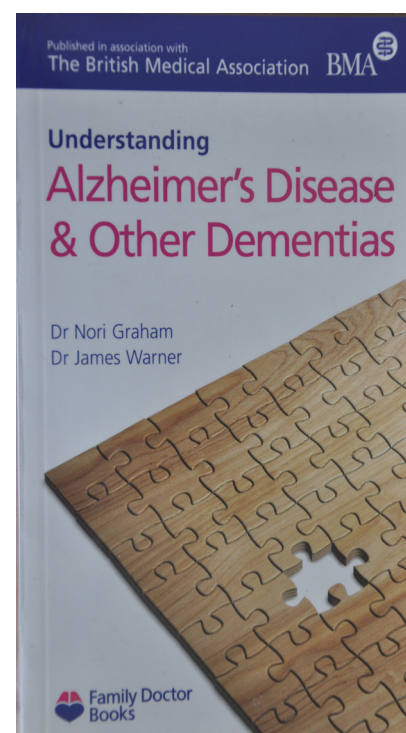
in dementia developed early on when I was researching into what the church can do to support carers. It's remarkably easy for carers to be invisible, so we set up a carers Christian Fellowship which helped them to share their journey of faith with each other."

Although it can be rewarding, watching someone you love and care for struggling with dementia can be emotionally draining and physically exhausting. Anecdotally, a lot of carers report going through a deep depression because of the impact this can have on their lives. Julia said, "My own depression in the past has helped me identify with what they are going through. The faithfulness of the carers really strikes me; it has to be real and relevant. I am very humbled by a lot of carers and people with dementia. Glib comments do not help – they are a way of dismissing the very real struggles people are wrestling with."

Emotional memories can often be very strong in people with dementia and those can act as an anchor in times of distress. Julia said, "People with dementia can find themselves in a spiritual wilderness, but you can see how people can respond even when cognitive impairment is profound, with things like responses to Bible readings, prayers and hymns."

Is dementia really part of God's plan? Julia said, "It is very hard and it constantly causes me to question my faith which is a good thing. I have to hold on to my belief that God loves that person and it is this that strongly motivates a lot of carers. Those moments of intense pain are hard to reconcile. We wonder what they can do to help alleviate that suffering. It's very painful but not a reason to not do the work. I feel that by meeting the challenge, our lives are enriched."

Julia said, "We should respect our elders and we can learn from people with dementia. Relationships are very important to them. It's all about heart; they are freer to express love and warmth. Dementia is talked about more openly now, but there is still a long way to go."



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