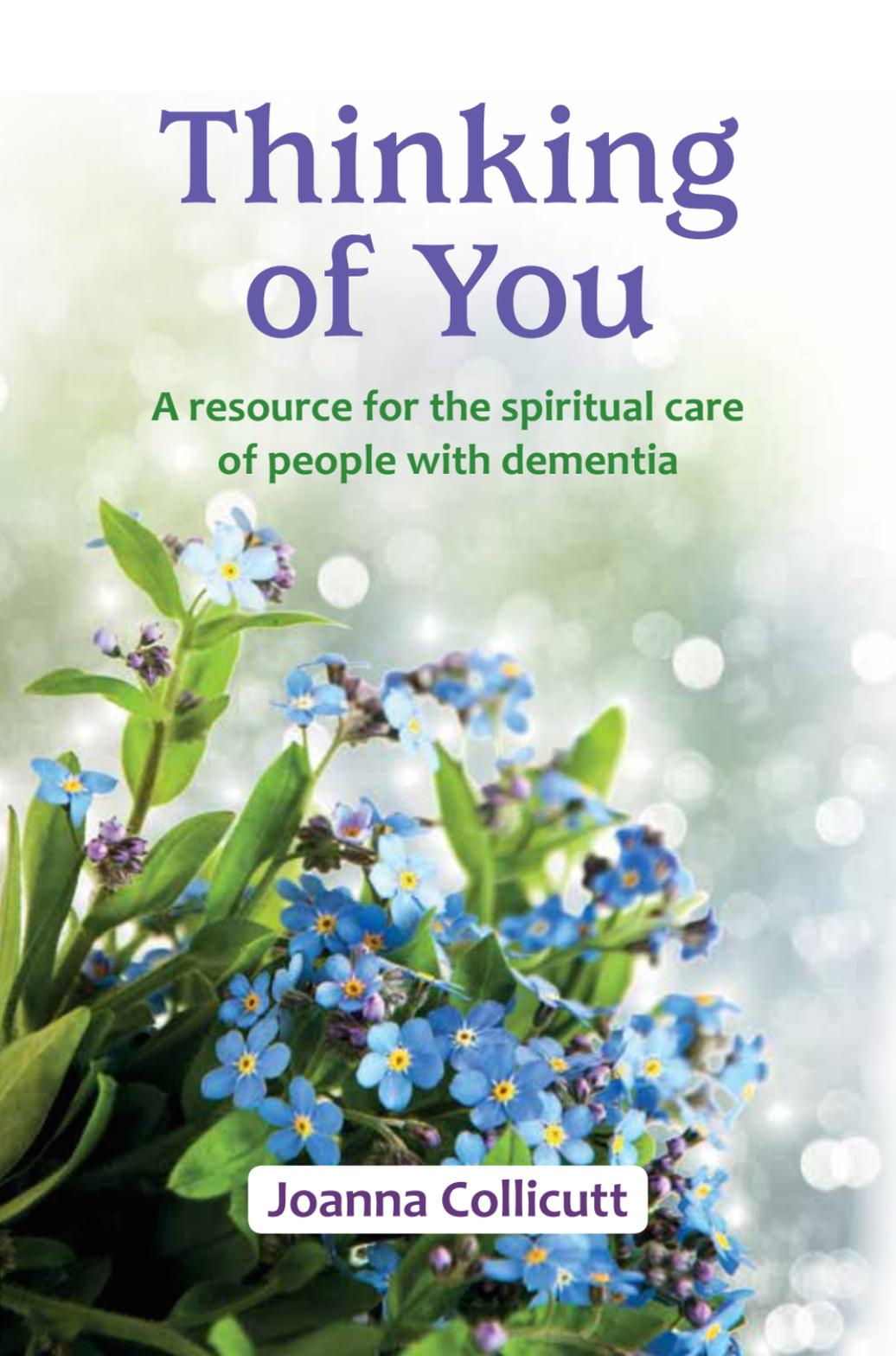


# Thinking of You

A resource for the spiritual care  
of people with dementia



Joanna Collicutt

# Thinking of You

A resource for the spiritual care  
of people with dementia

Joanna Collicutt



## **The Bible Reading Fellowship**

15 The Chambers, Vineyard  
Abingdon OX14 3FE  
**brf.org.uk**

The Bible Reading Fellowship (BRF) is a Registered Charity (233280)

ISBN 978 0 85746 491 0

First published 2017

10 9 8 7 6 5 4 3 2 1 0

All rights reserved

Text © Joanna Collicutt

The author asserts the moral right to be identified as the author of this work

Cover image © Thinkstock

## **Acknowledgements**

Unless otherwise stated, all Bible quotations are from the New Revised Standard Version Bible, copyright © 1989 the Division of Christian Education of the National Council of the Churches of Christ in the United States of America. Used by permission. All rights reserved. • Bible quotations marked (GNT) are from the Good News Translation. Copyright © 1992 by American Bible Society. • Scripture quotations taken from The Holy Bible, New International Version (Anglicised edition) copyright © 1979, 1984, 2011 by Biblica. Used by permission of Hodder & Stoughton Publishers, a Hachette UK company. All rights reserved. 'NIV' is a registered trademark of Biblica. UK trademark number 1448790. • Extracts from The Book of Common Prayer of 1662, the rights of which are vested in the Crown in perpetuity within the United Kingdom, are reproduced by permission of Cambridge University Press, Her Majesty's Printers.

Extract on p. 109 'Prayer' © Brian Thorne (2013). In *Accompaniment to a Life* (The Norwich Centre), p. 14. Used with kind permission. • Poem on p. 144 © Doug Chaplin. Used with kind permission. • Poem on p. 178 © Richard Underwood. The poem is from his 'Dreams of the Soul Poetry Anthology' available free from <https://www.smashwords.com/books/view/606870>. Used with kind permission.

p. 24: electron microscope image of neurons with amyloid plaques © Thinkstock; illustrations on pp. 18, 20, 32–36, 40 and 75 by Laszlo Veres (Beehive Illustration); p. 37: photomicrograph of Lewy bodies © Suraj Rajan, licensed under CC 3.0.

Every effort has been made to trace and contact copyright owners for material used in this resource. We apologise for any inadvertent omissions or errors, and would ask those concerned to contact us so that full acknowledgement can be made in the future.

A catalogue record for this book is available from the British Library

Printed and bound by CPI Group (UK) Ltd, Croydon CR0 4YY

# Contents

Foreword.....	7
About this book.....	9
Acknowledgements.....	10
<b>Part 1: Thinking about dementia .....</b>	<b>11</b>
<b>Chapter 1</b> A medical approach to dementia: ‘Old-timer’s disease’? ...	14
<b>Chapter 2</b> A biological approach to dementia: the fading brain.....	29
<b>Chapter 3</b> A social approach to dementia: not gone but forgotten ....	43
<b>Part 2: Thinking about the person with dementia .....</b>	<b>57</b>
<b>Chapter 4</b> I think therefore I am? .....	59
<b>Chapter 5</b> Beyond ‘I think therefore I am’ .....	70
<b>Chapter 6</b> God thinks therefore I am.....	81
<b>Part 3: Thinking of you: the spiritual care of people with dementia .....</b>	<b>93</b>
<b>Chapter 7</b> Being present to the person with dementia.....	98
<b>Chapter 8</b> Meaning-making in dementia .....	111
<b>Chapter 9</b> Re-memembering the person with dementia .....	125
<b>Part 4: Thinking about us: dementia-friendly churches .....</b>	<b>140</b>
<b>Chapter 10</b> Full inclusion.....	144
<b>Chapter 11</b> Real belonging.....	154
<b>Chapter 12</b> Celebration.....	167
<b>Chapter 13</b> Connection.....	183
<b>Chapter 14</b> Safe enough to play.....	193

# Foreword

## by the Bishop of Dorchester

There are at least three reasons why I wish this lovely, thoughtful, spiritual, pastoral, professional and perceptive book had been available many years ago.

The first is that I was vicar of Holy Trinity Margate for eight years in the 1980s. Not surprisingly, given the demographic profile of the town, and of a significant percentage of the congregation, there were a large number of people living with dementia. Some lived with it in themselves, and others as spouses and carers. But, whoever they were, this had major consequences for the pattern of their lives. Looking back, I think we, as a church, could have responded much better than we did. A huge amount of help was provided, but we could have been much more intentional in our response, and Joanna's book would have helped us a great deal in achieving this, to the benefit of all concerned.

Secondly, as for many of my generation, the big 'D' now stands alongside the big 'C' in generating worry and fear. Again I found this book an enormous help in that Joanna so carefully distinguishes between the normal process of ageing, including memory loss, and dementia. But, more than that, her approach to the 'fourth age' is very refreshing. It is all too easy just to label it as a time of diminishment and to miss what can be appreciated and celebrated.

But my third reason is much more personal. My own mother lived with dementia for a number of years before she died. It was very distressing to see the person I had known for so long seeming to fade away. Like so many others, I found it very difficult to cope with, and failed to respond in ways that she and I would have found benefited both of us. While this book would not have changed what we were facing together, it would have helped me a great deal in my response over the years.

## 8 THINKING OF YOU

So, if you are a leader of a church, or a member of a congregation, that has a large number of people living with dementia; or if you wonder what the future may hold for you as the years creep on; or if dementia is part of your lived experience—my hope and prayer is that these pages will be of benefit both to you and to those around you.

Rt Revd Colin Fletcher  
**Bishop of Dorchester**

August 2016

## About this book

Some years ago, in a move that was ahead of its time, Bishop Richard Harries set aside funds within the Diocese of Oxford for ministry among older people. This project came to be called ‘Spiritual Care for Older People’ (SCOP). The work of SCOP addresses several aspects of the spirituality of ageing, one of which is living well with dementia.

This book is a joint project between the Diocese of Oxford and the Bible Reading Fellowship, and it puts in one place the material that I have used in SCOP training on dementia with churches in Oxfordshire, Berkshire and Buckinghamshire over the last five years. In some of my training sessions, people have been interested in the theological questions raised by dementia; in others, they have wanted to know how to make their churches more dementia-friendly; most often, people seem to want to know more about the condition itself. Dementia still seems to be a mystery to many, and knowing more about what it is takes away some of the fear.

This book covers all of these topics in a logical order, and it makes most sense to start at the beginning and work through. However, if you are anything like me, you may want to dip into the chapters that interest you, and it is possible to do this as they are relatively self-contained. If you can’t be doing with theory and want to get straight to the practical tips, then these can be found in Part 4. When reading those chapters that refer to government legislation (particularly Chapters 3 and 14) please be aware that this often varies between the different parts of the UK and is in a continuous process of development, so it is wise to follow weblinks for updates.

## Part 1

# Thinking about dementia

Dementia seems to be all around us. It's there when we turn on the television or radio news bulletins, or open our daily papers. Most of us could name celebrities who have been affected by dementia—Omar Sharif, Prunella Scales, Margaret Thatcher, Ronald Reagan, Iris Murdoch, Terry Pratchett and so on. Closer to home, dementia is likely to have touched the lives of some of our family members, friends or acquaintances.

But what exactly is it?

The word 'dementia' literally means a loss of mental faculties (from the Latin *mens*, which means mind). It's an effective shorthand word but it doesn't in itself tell us very much. Think for a moment about someone you know who has dementia and ask yourself how many of the following apply to him or her:

- problems in thinking or remembering
- being elderly
- having a medical diagnosis such as Alzheimer's disease
- taking prescribed medications
- depending on others for personal care
- showing aggressive or other challenging behaviour
- withdrawal from previous roles and responsibilities in the community
- absence from social and family gatherings
- financial pressures due to care bills
- close relations who are suffering from stress
- vulnerability to exploitation and abuse
- living in a specialist residential care setting

## 12 THINKING OF YOU

This exercise should give you a sense of the many things that can be covered by the word ‘dementia’. It is not as simple as it may first appear, and there are a number of ways of looking at it.

Most people take the view that dementia is a kind of *illness* with a biological cause (like cancer). On this view, it is important to find ways of diagnosing it accurately and to pursue medical research aimed at developing a cure.

Some take the view that dementia is a particular form of ageing that involves unusually severe cognitive decline, seeing it more as a sort of psychological *disability* (like autism). On this view we might want to be a bit more cautious about saying that an affected individual is ‘ill’, and instead of talking about a cure we would focus on managing the disability.

Others view dementia as *something that happens to a social group*—to a couple or family, not just to the person who is identified as the ‘patient’. On this view ‘those affected by dementia’ doesn’t just mean individuals with the diagnosis, but every member of their social circles who are touched by its effects.

Yet others would take a more radical position and point to the way that societies label, marginalise and even incarcerate some individuals whom they see as no longer useful, or whose very existence challenges their values. (For example the modern age has placed a high value on rational thought, and this means that it cannot really accommodate those who can no longer think rationally.) On this view, dementia is *something that societies do to individuals*.

This book acknowledges that there are elements of truth in all these views (and also some problems with each of them). In fact, we need them all—the biomedical, psychological and social—to do dementia full justice. And there is more: any condition that involves the mental faculties is likely to have a deep *spiritual* impact. Indeed, in our society many people assume that the mind *is* the spirit. That’s one reason we

find dementia so challenging: if the mind has gone, has the spirit also flown?

While the different sections of the book each focus on these different aspects of dementia, the book as a whole brings them all together, seeing dementia as something that affects the whole of human life, structured around 'thinking of'. Part 1 lays some basic foundations by looking at dementia from a biomedical and social point of view. These foundations need to be in place if we are to explore 'ultimate' questions about the sense of identity and spiritual life of the affected person that form the focus of Part 2. Parts 3 and 4 have a practical emphasis: Part 3 looks at the principles and effective practice of spiritual care of individuals with dementia; Part 4 goes wider and looks at how churches can become more 'dementia-friendly' by reaching out to, welcoming and valuing all affected by dementia.

## Chapter 1

# A medical approach to dementia: 'old-timer's disease'

When she was a little girl, our daughter misheard the phrase 'Alzheimer's disease' as 'old-timer's disease'. It was an understandable mistake. On the basis of her experience with grandparents and older members of our church congregation, she had got the idea that when people grow old their thinking becomes slow; they become hard of hearing and so do not always 'get' what is going on; they repeat the same stories; they seem set in their ways; they easily mislay items or get into a muddle; and they forget the words for quite simple things, including the names of their own grandchildren! She thought this (or something quite like it) was what people meant when they spoke of dementia.

Most experts would say that these sorts of familiar, age-related changes are *not* dementia, and that dementia is quite distinct from 'normal ageing'. Furthermore, it is possible to develop dementia in early adulthood or midlife, so it isn't simply about being elderly.

Nevertheless, it's hard to distinguish between the early stages of dementia and just being a typical 'old-timer'. This is why specialist tests are needed to make a diagnosis. There is actually a lot of overlap between the problems experienced by older people who will go on to develop dementia and those who won't.

This talk of abnormality, disease and diagnosis tells us that we are entering medical territory, and in this chapter we will take a medical approach to understanding dementia.

## Dementia is a symptom

In medical terms, dementia is a symptom (or group of symptoms) rather than a disease.<sup>1</sup> Just as a fever tells us all is not well with the body, dementia tells us all is not well with the brain. But, while fever is simple to measure with a thermometer, dementia is more complex. It is usually described as a *gradual, irreversible decline in mental abilities*—it has a time course. So, to be sure it really is dementia, we need to see if the problem changes over time, either naturally or in response to simple treatment.

If a person gets confused and muddled but this doesn't last very long, then this isn't dementia. If we can find a simple way to treat the person, such as giving sufficient fluids, and the confusion disappears, then it isn't dementia. If a person shows a decline in cognition<sup>2</sup> but this stabilises and does not get worse for several years, then this is not dementia. But if the problem goes on for some time, doesn't respond to simple treatment and is getting progressively worse, we can say it is dementia.

## Ageism: don't assume it's dementia

It is easy to jump too quickly to the conclusion that someone has dementia, especially if he or she is elderly. If a young adult becomes confused, disorientated and agitated we are likely to assume that illicit drugs or excessive alcohol are to blame; yet with an older person we will readily consider dementia. This is simply ageism: older people get drunk too! They also take quite a lot of *prescription medication and this can sometimes have unwanted side effects* that impact on cognition.

More importantly, older people can be prone to temporary bouts of confusion that do not signify dementia. Other health conditions such as thyroid problems can mimic dementia. Like young children, older people are very sensitive to *changes in their body physiology*. In hot

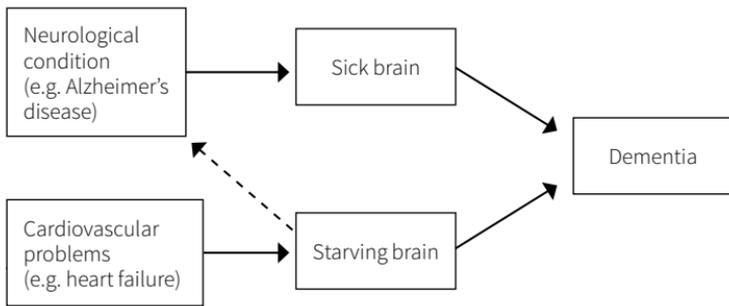
weather they can easily become dehydrated, and this can make them confused. If they have a chest infection, a urinary tract infection or another type of infection, this can also make them confused. Indeed, confusion may be the first sign that an infection is brewing. As their physiology returns to normal, thanks to hydration or antibiotics, so their cognition returns to normal. They often have no idea they have been confused and there is usually no need to mention it at all; it can be distressing and embarrassing to think you lost control of your own behaviour, even if only for a while.

*Depression* is a less obvious but nevertheless significant problem. Those of us who have experienced depression will know that when it hits it can be very difficult to think straight, remember information and make decisions. Depression also slows us down. These cognitive impairments can persist unchanged for quite a while if the depression isn't treated, but can be reversed once treatment takes effect. Depression is common in all age groups and is a particular feature of old age. This is probably because people are more likely to experience significant bereavements and other losses in later life. This, together with difficulty in getting out and about to social gatherings, leads to loneliness. Health problems, including poorly managed pain, play their part in lowering mood. It is estimated that one in five older people living in the community is affected by depression, and this rises to one in four of the residential care home population. Yet, many older people do not get the treatment for depression that they need and deserve. This is partly due to ageism again. There is an unfortunately common attitude that depression is a normal part of ageing—surely it must be depressing to get old. Depression is also missed due to the tendency among both ordinary people and some healthcare professionals to jump to the conclusion that an older person who is having persistent problems with thinking must be developing dementia. But depression should always be considered. It is a treatable health condition (medication and/or talking therapies are very effective) and therefore the cognitive problems that go with it are reversible. They do not signify dementia.

Finally, the effects of *age-related hearing loss* (an extremely common condition) can look rather like dementia. The person doesn’t follow the conversation, appears to have forgotten what he has been told, gets defensive when challenged and may become socially withdrawn. It is sensible to organise a hearing test or to check out the batteries in an existing hearing aid before considering dementia as an explanation.

## Dementia is a symptom of something

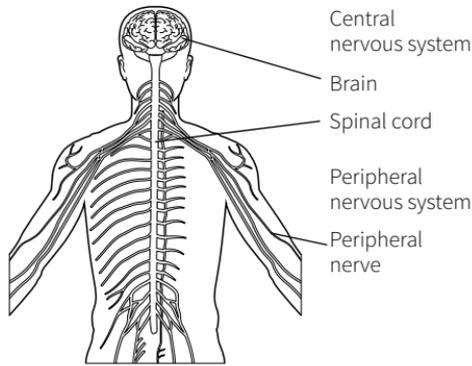
Even when we are sure that dementia—gradual, irreversible decline in cognitive function—is present, we have only described the symptom. We need to find out what is behind it. Dementia tells us that all is not well with the brain—that there is some sort of process at work that is gradually making more and more of its parts weaken and die. Essentially this is down to either brain sickness or brain starvation (see Figure 1). You could say that that dementia happens either because the brain is diseased or because its energy and oxygen supply are gradually being cut off.



**Figure 1** Flow chart showing how a sick or starving brain leads to dementia.

## Brain sickness: dementia as a symptom of a progressive neurological condition

Neurological conditions are disorders that affect parts of the nervous system (the brain, the spinal cord and the nerves that are all over and inside our body—see Figure 2).



**Figure 2** The nervous system.

People with neurological conditions may have problems in any area of human functioning. They can experience difficulties with movement and physical sensation, changes in their emotions, impaired cognition or all of these, depending on what parts of the nervous system are affected. A neurological condition is described as ‘progressive’ if it gradually gets worse over time.

Dementia only happens when a progressive neurological condition affects the parts of the brain concerned with cognition. Some progressive neurological conditions have a relatively minor impact on these parts; others have a major impact. For example, motor neurone disease has a minimal impact because it primarily affects parts of the brain to do with movement rather than thinking; multiple sclerosis sometimes has a significant impact; Parkinson’s disease often has a significant impact; and Alzheimer’s disease has a major impact. So, as illustrated in Table 1, dementia is rare in motor neurone disease and multiple sclerosis; it is more common in Parkinson’s disease; but it is the defining feature of Alzheimer’s disease.

**Table 1** Simplified summary of motor and cognitive problems in selected neurological conditions

Progressive neurological condition	Problems with movement	Problems with thinking
Motor neurone disease	Very severe	Relatively mild
Multiple sclerosis	Mild to very severe	Usually mild, but sometimes significant
Parkinson's disease	Significant to very severe	Moderate to significant
Alzheimer's disease	Mild	Significant to very severe

Of all the progressive neurological conditions, it is Alzheimer's disease that is most strongly identified with dementia, and which accounts for the majority of diagnosed dementia cases (about 60%). However, there are some other rarer conditions that are also important—for example Pick's disease (now more commonly known as frontotemporal dementia), Korsakoff's syndrome, Creutzfeldt-Jakob disease (related to BSE) and Lewy body disease.

## Brain starvation: dementia as a symptom of a cardiovascular condition

The brain needs oxygen to survive, and brain cells die very quickly if deprived of oxygen. Even if there is no progressive neurological condition at work and the brain itself is basically healthy, dementia can occur because of a disruption to the supply of its oxygen and nutrients. Like the rest of the body, the brain receives oxygen and nutrients such as glucose from the blood vessels that penetrate all its parts (see Figure 3).

## Chapter 6

# God thinks therefore I am

How are we to make sense of the experience of dementia theologically?<sup>1</sup> For the Christian any approach needs to be grounded in the belief that God is our creator and redeemer. It also needs to connect with a Trinitarian understanding of God as Father, Son and Spirit. It needs to be compatible with the Bible and also to acknowledge the importance of the community of faith—the Church.

This may seem like a big ask, yet we already have some clues as to a promising way forward. Paul's words about the Spirit helping us when we reach the limit of our intellectual capacities (Romans 8:26) are one; his words about God's strength being 'made perfect in weakness' (2 Corinthians 12:9) are another. But the logical place to start is at the very beginning, with the creation of humanity.

## God our mighty creator

'God created humankind in his image, in the image of God he created them; male and female he created them' (Genesis 1:27). We are made in the image of God. But what does this mean? Theologians have argued about this for centuries. Augustine of Hippo, whom we have already encountered in Chapter 4, wrote of a 'human trinity' that mirrors the Trinitarian nature of God.<sup>2</sup> For Augustine this human trinity consists of intellect, memory and love—the capacity to think, to remember and to be in relationship. This doesn't seem too unreasonable an idea until we are faced with individuals who do not have one or more of these capacities. Then it becomes problematic. Are these individuals not made in God's image? Or if they once had these capacities but have now lost them, has the image of God been removed from them?

One response to these questions is to turn to Jesus' command not to judge others (Matthew 7:1). He tells us we need to look to ourselves before pointing the finger at other people (Matthew 7:3; John 8:7). Also, and more fundamentally, he reminds us that only God knows and therefore only God can judge (Matthew 13:24–30; Luke 18:9–14). What was true at the time of Jesus is true now; even with our great knowledge of the mysteries of neuroscience, we can't read the mind of another person or look into his heart. Even if that person appears to all intents and purposes to have no intellect, memory, affection or even sentience, we cannot be absolutely sure. This is why people in vegetative states due to brain damage, deemed to lack sentience following scrupulous court inquiries, are nevertheless given both sedation and analgesia while their artificial life support is discontinued. As one surgeon puts it, 'In daily practice, physicians administer sedating narcotic analgesics to PVS [persistent vegetative state] patients simply because they are uncertain of and cannot measure their patients' discomfort... As science fails, we are left to rely on professionalism and the ethics of compassion.'<sup>3</sup>

So we can't be completely sure that any individual actually has lost all vestiges of intellect, memory and love in relation to his physical and social world. But even if we were able to be certain of this, there remains the question of whether that individual could still have these capacities in relation to God. The ability to think about, remember and love *God* (rather than the stuff of this world) is probably what Augustine had in mind when he talked of the human trinity; we are made in the image of God insofar as we have the capacity to relate to *God* in these three ways. In Chapter 4 we saw that this is what the Bible seems to mean by the human 'spirit'.

Is it possible, then, that a person may lose the capacities that underpin human spirituality as we usually understand it—becoming deficient in 'transcendence abilities'—and yet retain a capacity to receive the revelation of God? And might the reverse be possible—that a person could have a superb intellect, memory and capacity for relatedness yet still not be in touch with God? Swiss theologian Karl Barth (1886–1968) was convinced of it:

Is the revelation of God some kind of ‘matter’ to which man stands in some original relation because as man he [can]... take responsibility and make decisions in relation to various kinds of ‘matter’? Surely all his rationality, responsibility and ability to make decisions might yet go hand in hand with complete impotency as regards *this* ‘matter’!

Barth goes on to ask what implications this might have for people he (in the language of the time) describes as ‘those, who as far as human reason can see, possess neither reason, responsibility nor ability to make decisions: new-born children and idiots. Are they not children of Adam? Has Christ not died for them?’<sup>4</sup> Barth is saying we simply don’t get just how different the process of receiving divine revelation is from our normal human thinking, remembering and relating (Isaiah 55:8–9), and we shouldn’t make assumptions about what is going on between God and a person who, humanly speaking, is incapable in all these areas. Barth’s analysis is driven by a conviction that *all* are made in God’s image, and that this does not depend on incidental aspects of their make-up such as their race or abilities. He was writing in the context of the rise of Nazism, with its philosophy of eugenics and genocide, and his horror at this deeply affected his thinking. Barth’s approach is very helpful in many ways, though not without its limitations (the most obvious being that he doesn’t specify exactly *how* people receive divine revelation). Perhaps his most significant contribution to the issue of dementia is that, by downplaying the role of human abilities, he draws our attention to a very important theological theme—the *grace* of God.

## God our gracious sustainer

God didn’t just make the world, wind it up and watch it go. From the beginning God has remained deeply involved in this world. God sustains the whole cosmos—including us—and without him it would cease to be (Colossians 1:16–17). Yet most of the time we act as if we have forgotten this, treating life as a game that requires a mixture of

skill and luck. We feel as if we are essentially in control—that, when we encounter problems or obstacles, we can generally fix them ourselves or exert influence to get them fixed by others. When things go well we often feel this is due to our skill, or that we deserved a lucky break. When things go wrong we may blame ourselves, blame others or wonder if we are being punished. This is why, when we face an unanticipated crisis or uncontrollable adversity, we ask, ‘What have I done to deserve this?’ We are trying to work out the rules of play so that we can improve our skills, try harder and play the game better.

But, of course, this is totally wrong. Life is not a game to be played, but a gift to be received. It is God who is in control and who ‘makes his sun rise on the evil and on the good, and sends rain on the righteous and on the unrighteous’ (Matthew 5:45b). We don’t get what we deserve but what God graciously gives us. It’s not really about us at all; it’s about God.

If we bring this truth to bear on the subject of dementia we can see that, theologically speaking, the issue is not the cognitive and relational capacities of human beings but the cognitive and relational capacities of God. The question then becomes not so much whether people with dementia can receive divine revelation (as Barth would insist they can) but whether God thinks about, remembers or loves them.

In Chapter 5 we noted that the capacities of the prodigal son to remember his father’s house and to find a way back are important in making his story good. But much more important than either of these is the fact that the father has always had his son in mind and is waiting to welcome him home. The son’s return doesn’t take the father unawares; the father is watching and waiting. Even though, for a while, the son seems to have forgotten his father, the father has never forgotten his son.

This is one way we can understand what makes us human and therefore what constitutes the image of God in us. On this understanding, it’s not about any capacity of ours at all, but about the fact that God holds us in mind. The very creation and continuing existence of human beings happens because God intentionally holds us in mind: *God* thinks

therefore I am. This close relationship between God's active knowing of us, our creation and his continuing involvement in our lives is drawn out very beautifully in Psalm 139:

O Lord, you have searched me and known me.

You know when I sit down and when I rise up;  
you discern my thoughts from far away.

You search out my path and my lying down,  
and are acquainted with all my ways...

For it was you who formed my inward parts;  
you knit me together in my mother's womb.

I praise you, for I am fearfully and wonderfully made.  
Wonderful are your works;

that I know very well.  
My frame was not hidden from you,

when I was being made in secret,  
intricately woven in the depths of the earth.

Your eyes beheld my unformed substance.

In your book were written  
all the days that were formed for me,  
when none of them as yet existed.

How weighty to me are your thoughts, O God!  
How vast is the sum of them!

I try to count them—they are more than the sand;  
I come to the end—I am still with you.

**PSALM 139:1–3, 13–18**

In Psalm 8 the writer ponders even more deeply on the relationship between the thoughts of the Creator and their impact on human beings:

When I look at your heavens, the work of your fingers,  
the moon and the stars that you have established;

what are human beings that you are mindful of them,  
mortals that you care for them?

PSALM 8:3–4

On the face of it, these lines seem to be posing the question of why God would bother with puny little creatures like us, but some scholars<sup>5</sup> have seen something more intriguing here: they suggest the psalmist is instead pondering what it means to be human—‘what are human beings?’—and that he comes to the answer ‘that *you are mindful of them*’. That is, we are human precisely because God is mindful of us! If God were to stop keeping us in mind, we would cease to be. It follows from this that, whatever our cognitive capacities or incapacities, if we are held in the mind of God then we are human persons.

The ironic thing about dementia is that, through its relentless stripping away of mental capacities, it reminds us all of something we might otherwise forget—our utter dependency on God. For those affected directly by dementia, this reminder may take the form of surprising experiences of spiritual growth, even in the midst of profound loss and suffering. For the rest of us, reflecting theologically on dementia offers us an opportunity to re-examine our assumptions about who is really in control of our lives.

The Hebrew word that is translated ‘to be mindful of’ in some English Bibles is *zākar*. It has a range of meanings that include ‘remember’, ‘keep in mind’, ‘call to mind’ and ‘be concerned about’. It describes a kind of loving attentiveness, a calling to consciousness. It’s what we mean when we say to someone who is going through a difficult time, ‘I’ll be thinking of you.’

Of course, this sort of thinking is essentially remembering, so it is not surprising that the Hebrew Bible has many instances of individuals calling out to God to *remember* them or their cause (for example, Psalms 10; 20; 74). In response, we have God's assurance that he will remember his covenant promise and will not forget his people:

Can a woman forget her nursing child,  
or show no compassion for the child of her womb?

Even these may forget,  
yet I will not forget you.

See, I have inscribed you on the palms of my hands;  
your walls are continually before me.

**ISAIAH 49:15–16**

The New Testament, with its radical understanding of the grace of God, goes even further. Our relationship with God is not based on our race or religion but simply on the fact that God knows us. This is strongly indicated by two almost throwaway lines in Paul's letters. In Galatians he tells his readers that their lives have changed since they have come to know God through their faith in Christ, but then he corrects himself:

Formerly, when you did not know God, you were enslaved to beings that by nature are not gods. Now, however, that you have come to know God, *or rather to be known by God*, how can you turn back again to the weak and beggarly elemental spirits? How can you want to be enslaved to them again?

**GALATIANS 4:8–9 (my italics)**

Paul is reminding himself and his readers that it's not about what you know, or even who you know, but about who knows you. Why did he think this? The reason seems to have been his own experience. Something happened to him on the road to Damascus that turned his world upside down. He thought he knew all about the criminal Jesus of Nazareth, but he came to understand that it was Christ Jesus who

knew all about him. This was such a shock that it made him go blind for a while, but it seems he came to see this knowing as wonderfully affirming—something that enabled him to be fully himself, and which filled him with joy, delight and love:

For now we see in a mirror, dimly, but then we will see face to face. Now I know only in part; then I will know fully, *even as I have been fully known.*

1 CORINTHIANS 13:12 (my italics)

Paul was saved through God's knowledge of him. We might say that Paul discovered Jesus had always had him in mind. This is even clearer for the thief who hung next to Jesus on the cross and asked, 'Jesus, remember me when you come into your kingdom' (Luke 23:42). God's thinking not only brought these men into being; it redeemed them.

## God our loving redeemer

Just as God's creation and sustenance of the world are acts of grace, so is his sacrificial redemption of humankind. We can't redeem ourselves by trying to appease God, or even by trying to love God. We don't generate love; we participate in it: 'In this is love, *not that we loved God but that he loved us* and sent his Son to be the atoning sacrifice for our sins' (1 John 4:10, my italics).

The language of cultic sacrifice in this verse from the first letter of John may feel a bit alien to us in the West in the 21st century, yet the day-to-day sacrifices made by those who care for loved ones with dementia are all too familiar. We see the regular setting aside of their own needs in order to pay full attention to the needs of their loved ones; hours spent in largely thankless acts of physical and psychological care, even drudgery; acceptance of the confines of the family home, or lengthy visits to often dismal residential care facilities, in order simply to be present and available. All of this can be seen as both self-sacrificial and redemptive.

*Thinking of You* is a comprehensive introduction to the subject of dementia. This accessible book is a practical resource for those directly affected by the condition, their immediate family and carers, and those seeking to offer them pastoral care and encourage continuing spiritual growth. Importantly, the author addresses the spiritual care of the affected individual and how to help churches support them and their carers. The final section includes resources for ministry in residential care homes.

**The Revd Canon Dr Joanna Collicutt** is Advisor for Spiritual Care for Older People (SCOP) in Oxford Diocese, a role which involves the planning and delivery of training courses on the topic of dementia for clergy, ordinands and lay pastoral care teams. She is a clinical neuropsychologist with many years' experience of working with people living with conditions affecting the brain, including dementia. Her other books include *When You Pray* (BRF, 2013).



[brf.org.uk](http://brf.org.uk)