

WAVERLEY ABBEY INSIGHT SERIES



INSIGHT INTO  
**DEMENTIA**

Rosemary Hurtley  
Foreword by Dr Daphne Wallace

**CWR**

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Concept development, editing, design and production by CWR

Printed in China by C&C Offset Printing

ISBN: 978-1-85345-561-2

Rosemary has described dementia and its effects in an accessible way. Her insights enable you to see the person and not the dementia. By including scriptures throughout the book she has connected the relationship and hope that stems from faith in God and coping with a debilitating illness.

**Sharon Blackburn RGN RMN**

Written with insight and compassion, including carefully chosen Bible readings and prayers to give comfort and strength, this is an invaluable guide by someone who really understands because she has been there herself. It would have been wonderful to have had this resource when I really needed it.

**Joanna Howse, carer of a husband with dementia**

From a wealth of both personal and professional experience Rosemary Hurtley has written clearly and succinctly. It is only too easy to discuss dementia care with bias and emotive comment, bringing feelings of guilty obligation. This book, on the other hand, will leave its readers accurately informed, empowered, and greatly encouraged.

**Marion Osgood, writer, and Hugh Osgood, international Bible teacher**

I found this to be a practical, informative text reflecting contemporary knowledge and approaches to dementia care. It distinguishes itself from the many other books about dementia currently available by its Christian spiritual context.

**Clive Evers, Alzheimer's Society**

This is a much needed resource with all the things you need to know about how dementia impacts on a person and ways to support them.

**Claire Craig, Occupational Therapist**

## **WAVERLEY ABBEY INSIGHT SERIES**

The Waverley Abbey Insight Series has been developed in response to the great need to help people understand and face some key issues that many of us struggle with today. CWR's ministry spans teaching, training and publishing, and this series draws on all of these areas of ministry.

Sourced from material first presented on Insight Days by CWR at their base, Waverley Abbey House, presenters and authors have worked in close co-operation to bring this series together, offering clear insight, teaching and help on a broad range of subjects and issues. Bringing biblical understanding and godly insight, these books are written both for those who help others and those who face these issues themselves.

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## FOREWORD

Although general awareness and understanding of dementia has improved there is still a long way to go before we achieve anything like that achieved in the last fifty years for cancer. In the year since publication of the National Dementia Strategy for England it is increasingly evident that we have much misunderstanding and 'dis-information' to counter.

I welcome this book. Many carers with a Christian faith struggle to understand the pain and distress that can go with dementia in the context of their faith in a loving God. This book should go a long way towards helping them grapple with such difficulties. The provision of suggested activities, reflection and prayer at the end of each chapter helps greatly to aid reflection, particularly in a person-centred way and leads to meditative prayer. The use of poetry and biblical references assists the prayerful examination of the issues and our understanding and acceptance of them. The quotes at the head of each chapter are also helpful and thought provoking.

The first chapter gives a clear outline of the current knowledge of dementia in its different forms, and the impact of the illness on the person with dementia and their family and carers. One helpful aspect of this chapter is that it makes clear that dementia is not a unitary disease and, though Alzheimer's disease is the most common form, other pathologies are not uncommon and may present different problems. The second chapter looks at the journey to be travelled by the person with dementia and their family. In outlining current understanding of memory and other changes with normal ageing it also describes the process of diagnosis. The sections on the experience of dementia are informative and should help carers to a greater appreciation of the impact of the diagnosis.

## FOREWORD

Aspects of treatment and the need for a positive message to counter the old idea that ‘nothing can be done’ are outlined. A discussion of wellbeing and avoidance of ill-being are well explored, again with helpful examples and vignettes. The need for help and support, particularly for carers, is tackled with an outline of the various experts who should be there to help. With increasing pressure for more choices and care options it is helpful to have the outline of issues to be considered, especially in the later stages of the illness.

Much that is involved in spiritual care runs like a thread throughout the book but in the last chapter the specific issues involved in helping the person with dementia to maintain their spiritual life are thoughtfully explored, as is the need to recognise this in the context of care homes, which is welcome.

The last, very helpful, part of the book provides sources of further information and material, and elaborates on some of the systems and methods referred to in the text.

Overall this book is a welcome addition to the current literature on dementia and particularly useful to members of the Christian community.

Dr Daphne Wallace

Retired psychiatrist and person with dementia

## INTRODUCTION

Dementia isn't when you can't find your car keys; it's when you're standing at the door and you don't know what they're there for.<sup>1</sup>

In Proverbs 23:33, we read: 'Your eyes will see strange sights and your mind will imagine confusing things' – this could be a description of living with dementia. Dementia! The very word seems to conjure up anxieties about being out of control of one's life, or images of a prolonged death sentence. There is so much fear, stigma and ignorance attached to it; as indeed there is with the ageing process itself. But we cannot choose to ignore dementia. We may have a loved one who has been diagnosed with it. We may have a friend who has a partner or parent suffering from the effects of it. In one way or another, many of our lives have been, or are, touched by it.

In this book, we will be taking a look at what it means to have dementia; what it is, the journey onwards from the initial diagnosis, dementia care, help and options and, of course, spiritual care. We will be exploring dementia and what it feels like, its impact; we will also see how as a church community we need to understand it, deciding strategies to include and show unconditional love to people with dementia, and their families.

Issues of care are crucial to address; it is important that quality services can be provided for our ageing population and, of course, we need to engage older people in what this whole package will look like. Because of the changes in society's attitudes and social engagement, use of technology and new health sciences, we will need imagination to find new ways of delivering care.

## INTRODUCTION

It's my hope that you will find this book informative, helpful and encouraging; that if you are walking down the dark path of this illness yourself, or accompanying a loved one, you might find within these pages the strength, hope and assistance you need for the journey.

Rosemary Hurtley  
January 2010





## CHAPTER ONE

# WHAT IS DEMENTIA?

‘Rise in the presence of the aged, show respect for the elderly  
and revere your God.’ (Leviticus 19:32)

‘... do not despise your mother when she is old.’  
(Proverbs 23:22)

### INTRODUCTION

Our population is an ageing population. More than 13 million people in the UK will be over sixty-five by 2031. Most of those will be over eighty-five, with women outnumbering men.<sup>1</sup> Will this fact make age discrimination more or less of an issue? With such a diverse population, it may not be viable to still discuss older people as a group, and many will continue to work past retirement age. However, as the population ages, more people will need care and support – 50 per cent of those over seventy-five will have life-limiting illnesses, and dementia will affect one in four over the age of eighty-five.

But what *is* dementia?

In this chapter, we will examine what ‘dementia’ actually is, as well as thinking about age in general. Let’s look at some facts and truths about ageing.

### **SOME FACTS ABOUT AGEING**

- Ageing is not a disease, but part of the normal life process.
- Everyone ages differently; we become more diverse with age. Our bodies and minds become less efficient but we are still able to improve and develop, with active training.
- The process affects our physical, psychological, personality and cognitive aspects.
- Main contributors to dependency are a lack of mobility, poor mental health and cognitive problems.
- Successful ageing and quality of life is closely linked to maintaining and developing relationships, retaining contact with society, and having opportunities to develop, improve, maintain function and learn new things.
- Ageism and attitudes which stereotype older people frequently influence expectations, practice and outcomes, and need challenging. Western society holds in high esteem the values of beauty and eternal youth rather than the intrinsic value of all ages and the wisdom of elders. Some people feel both invisible, and that they are forced to disengage and retreat when they age – as society expects them to. However, this attitude is changing with the Baby Boomer generation. The Bible makes it clear that we should respect age and the wisdom of experience of the old (see, for example, Lev. 19:32).
- Health and wellbeing are influenced by the degree to which we are engaged and involved in the environment around us, social contact and an active interest in what is going on, and our relationships, as believers, vertically towards God and horizontally towards each other.<sup>2</sup>

## **DEMENTIA IS ...**

Dementia is an irreversible and progressive intellectual disability affecting key functions of daily life and caused by a group of disease processes. The symptoms that all people with dementia share are the true attributes of the disease, but what they don't share can rarely be attributed to dementia. Dementia is an umbrella term which describes a serious deterioration in mental functions, such as memory, language orientation and judgment. There are many types; Alzheimer's disease accounts for two-thirds of cases, and is the best known.

Early symptoms of dementia may include loss of memory – for example, forgetting the way home from the shops, or being unable to remember names and places, or what happened earlier the same day; and mood changes – particularly as parts of the brain that control emotion are affected. People with dementia may also feel sad, frightened or angry about what is happening to them. Communication problems – a decline in the ability to talk, read and write may also be an early symptom in some forms of dementia.

Dementia is progressive, which means the symptoms will gradually get worse. How fast dementia progresses will depend on the individual, their environment and the underlying pathology. Each person is unique and will experience dementia in their own way.

## **WHO GETS DEMENTIA?**

There are about 825,000 people in the UK with dementia; the condition is expected to double in the next forty years. Dementia mainly affects older people. However, it can affect younger people: there are approximately 15,000 in the UK under the age of sixty-five who have dementia, requiring specialist services. It can affect both men and women.<sup>3</sup>

Scientists are investigating the genetic background. It does appear that in a few rare cases, the diseases that cause dementia can be inherited. So, some people with a particular genetic make-up have a higher risk than others of developing the disease. But generally, there is no single factor – probably a combination; some can develop their symptoms silently, or something can trigger it.

## **TYPES OF DEMENTIA**

### **ALZHEIMER'S DISEASE**

Senile dementia of the Alzheimer's type is a progressive global impairment of intellectual then daily living skills, slowly eroding abilities over a period of years, arising from changes in the brain (plaques of protein in brain tissue and tangles of abnormal nerve fibres in cells). This is the most common type of dementia. It is named after the German scientist Alois Alzheimer, who identified the condition over a century ago. He studied a woman in an asylum in 1901 until her death in 1906 and found she had short-term memory loss and disorientation. After her death, he studied her brain and discovered she had protein deposits and amyloid plaques and tangles, which characterise dementia.

Alzheimer's affects one in twenty over the age of sixty-five and one in five over the age of eighty. Risk factors include genetic inheritance (in early types particularly), also smoking, severe whiplash, head injury, high blood pressure and high cholesterol. Alzheimer's is diagnosed when other causes such as infections, vitamin insufficiency, thyroid deficiency, tumours or depression are excluded. Some drugs may be offered in the earlier stages to stabilise symptoms for a limited period.

## WHAT IS DEMENTIA?

### VASCULAR DEMENTIA

Vascular dementia is the second most common type of dementia caused by problems of the blood supply to the brain. The conditions that cause or increase damage to the vascular system include high blood pressure, heart problems, high cholesterol and diabetes. It is therefore important to have these conditions treated as early as possible. There are many types of vascular dementia but the most common is caused by a single stroke or a series of small strokes, sometimes referred to as multi-infarct dementia (affecting about 20 per cent of all dementias). This type is often accompanied by slurred speech or weakness down one side of the body. The other main type is small vessel disease. It is also possible to have a combination of both types.

People with this type of dementia will experience problems with concentration, communicating, depression and memory, and they sometimes have periods of acute confusion. The stepped progression means that symptoms can remain at a constant level and then suddenly deteriorate. People with vascular dementia can also experience hallucinations, delusions, wandering and getting lost, restlessness and incontinence.

Risk factors include a history of stroke or hypertension, high cholesterol, poor physical activity, high intake of alcohol, smoking, and eating a fatty diet.<sup>4</sup>

### LEWY BODY DISEASE

This has recently come to light and is named after the person who discovered small protein-like bodies distributed in specific parts of the brain resulting in memory loss, language and reasoning difficulties, hallucinations, delusions, fluctuation, and muscular rigidity similar to Parkinsonism, balance, tremor and slowness of movement. This can sometimes be misinterpreted as laziness. It represents 10–15 per cent of dementias.

### CREUTZFELDT JAKOB DISEASE

This is a transmissible disease due to a slow 'virus' which can lie dormant for a number of years. This is caused by abnormally formed clusters of protein (prion) in the central nervous system, resulting in sponge-like holes in the brain matter. People with CJD normally die within six months; it is a very rare condition that starts with memory loss and mood changes, quickly progressing to complete loss of function and dependency requiring full nursing care.

### FRONTAL LOBE DEMENTIA (INCLUDING PICK'S DISEASE)

This is characterised by personality change such as lack of insight and empathy, inappropriate behaviour, loss of inhibitions; the sufferer becomes easily distracted and develops compulsive tendencies. In fronto-temporal dementia, damage is usually focused on the front part of the brain. At first, personality and behaviour are more affected than memory.

### OTHER TYPES OF DEMENTIA

There are a number of other illnesses and chronic conditions that can also include dementia-like symptoms, often in the later stages of the illness. These include:

- late onset Parkinson's disease
- Huntington's disease
- multiple sclerosis
- thyroid deficiency
- dementia caused by head injury
- HIV-related dementia.

## WHAT IS DEMENTIA?

Dementia can also occur in those who have a history of alcohol abuse (Korsakoff's syndrome). These people find it difficult to learn new skills, lack insight into their condition, and invent stories to fill the gaps in memory (confabulation). Some recover if they stop drinking and adopt healthy living and a diet with adequate vitamins and nutrition. If they persist in drinking, they are likely to need long-term care. For example, Lucy's story:

Last Christmas Dad's neighbour rang me, concerned she had not seen his lights on for a few days. When I turned up, I found he had collapsed on the kitchen floor with hypothermia. He had been lying there for possibly three days. After four months in hospital, we were told he had alcohol related dementia and was sectioned by the Mental Health Act before his move to a suitable residential home. It was a shock, as the signs of dementia were not at all on our radar. Dad does not know where he lives and makes up stories, as he cannot separate fact from fiction. We struggled to get information; we did not know what questions to ask or what was expected of us. But we now all have a better relationship with him than we have had for years.

Dementias present with difficulties of judgment, articulation, understanding and insight. However, other conditions can present as dementia with impairment of memory, disorientation, poor concentration, delusions and hallucinations.

### **COMMON MISUNDERSTANDINGS WITH DEMENTIA**

The chart on the following pages shows some common misunderstandings of behaviour in daily life situations.<sup>5</sup>

## INSIGHT INTO DEMENTIA

<b>Behaviour</b>	<b>Frequent explanations</b>	<b>Possible causes due to changes in the brain</b>
Getting into the wrong bed/sitting in someone else's room	Lonely, disorientated or over-sexed; needing companionship	Cannot recognise the environment
Dropping things	Clumsy	Movement disorder due to changes in the brain or stroke
Not always recognising sounds or speech	Poor hearing; being difficult	Inability to recognise and interpret sounds or language
Unable to converse but able to sing without any problem, eg hymns, songs	Attention-seeking or uncooperative	Language problem due to brain damage, but the areas in the brain responsible for melody and rhythm not damaged (they are located in another part of the brain)
Unable to get dressed	'Senile', lazy, attention-seeking	Dressing apraxia, a condition of the brain which leaves a person not knowing how to perform particular actions previously learnt in daily living skills, or movement disorder

## WHAT IS DEMENTIA?

<b>Behaviour</b>	<b>Frequent explanations</b>	<b>Possible causes due to changes in the brain</b>
Repeating the same words over and over again	'Senile'	Damage to the front part, or the language part, of the brain
Bumping into things	Blind; forgetful	Unable to recognise objects, or to see the whole of the visual field in front due to changes in the brain affecting the way the environment is interpreted
Accusing people of assault	Troublemaker	Inability to recognise difference between themselves or others
Does not recognise faces	Rude; apathetic; blind	Inability to recognise faces due to brain damage

### **IS THERE A CURE?**

Most forms of dementia cannot be cured, although research is continuing into developing drugs, vaccines and treatments. Drugs have been developed that can temporarily alleviate some of the symptoms of some types of dementia, particularly for moderate stages. These drugs are known as acetylcholinesterase inhibitors; people with vascular dementia are not normally given these drugs.

The National Institute for Health and Clinical Excellence (NICE) revised guidance on acetylcholinesterase inhibitors to treat some types of dementia (issued in 2006) recommends that people in the moderate stages of dementia should be given treatment with one of those drugs (see [www.alzheimers.org.uk](http://www.alzheimers.org.uk)).