

Understanding **Dementia**

Dr Nori Graham & Dr James Warner

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IMPORTANT NOTICE

This book is intended not as a substitute for personal medical advice but as a supplement to that advice for the patient who wishes to understand more about his or her condition.

Before taking any form of treatment
YOU SHOULD ALWAYS CONSULT YOUR MEDICAL
PRACTITIONER

In particular (without limit) you should note that advances in medical science occur rapidly and some of the information about drugs and treatment contained in this booklet may very soon be out of date.

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Introduction

Who is this book for?

- You think your memory is going?
- Your father/mother is behaving oddly?
- Is it Alzheimer's disease?
- Is Alzheimer's disease the same as dementia?

If these are the sorts of questions that you are asking yourself, this book is for you. Dementia is a disease of the brain. First we define dementia before going on to list the symptoms. This chapter helps you decide whether you, a member of your family or a friend may have dementia.

Next we discuss treatment and how to get help, and after that we give some tips on how to make the best of life if you or a loved one is found to have dementia. Then we consider how future developments may change the outlook for people with dementia, and describe some common questions and give some

answers. Finally, we describe how the brain works. Some of that chapter is a bit technical; you may decide to skip it.

There is a lot of myth and misinformation about dementia. This book is intended for anyone who has, or may be worried that they or their family and friends have, dementia.

It is also for people who live or work with someone with dementia. We hope that by reading this book you will have a better understanding of what causes the illness and how it is diagnosed and treated.

What is dementia?

'Dementia' is a term used to describe any condition where a variety of different brain functions such as memory, thinking, recognition, language, planning and personality deteriorate over time.

Dementia is not part of normal ageing. Everyone gets more forgetful as they get older; that does not mean that they have dementia. The most common type of dementia is Alzheimer's disease, but there are several other types.

Who gets dementia?

Dementia is common. It is estimated that there are almost three-quarters of a million people with dementia in the UK and this number is rising. As people get older the risk of dementia increases rapidly. It is estimated that one in six people aged over 80 years has some type of dementia.

Dementia can affect anyone. Prominent people such as Ronald Reagan, Harold Wilson, Margaret Thatcher, Iris Murdoch, Terry Pratchett and many other well-known names from all walks of life have

developed dementia. It is a global problem, occurring in all ethnic groups and social classes. No one is immune.

It is important to recognise when someone may have dementia. A swift and accurate diagnosis is important while people can still plan their lives and have a say in their treatment. Getting a diagnosis is also helpful to explain why someone isn't getting on as well as they used to and ensures that they get the necessary help. It is also reassuring to be told if you don't have dementia.

Facts and figures about dementia

Dementia is common; about one in every 90 people in the UK has dementia. In 2008, it was estimated that there were 700,000 people in the UK with dementia and this will rise to 1 million by 2025.

Dementia is rare below the age of 65, but can occur in people as young as 30. About 1 in 20 people over the age of 65 has dementia, rising to about 1 in 6 of people aged over 80. Dementia is becoming more common because the biggest risk factor for dementia is getting older and people are living longer.

About two-thirds of people with dementia live at home. Almost three-quarters of people living in care homes have dementia. People who develop dementia often live for many years with the condition. It is not uncommon for someone to live seven to ten years after a diagnosis and then to die of something else. Nearly everyone who has dementia will get worse over time and many people will eventually need to be cared for because they cannot live safely alone.

Diagnosing and treating dementia

The prospect of receiving a diagnosis of dementia is frightening. Other conditions such as depression and some physical illnesses (for example, Parkinson's disease) can look like dementia. Dementia can be diagnosed only after careful assessment by a doctor.

In the last 15 years there has been a great deal of research into treatments of dementia and drugs are now available to treat memory loss and problems with thinking. There has also been a lot of progress in understanding how someone with dementia, and families and carers, can be supported.

In this book we describe how dementia is diagnosed and treated. It is important to remember that not all the services and facilities described in this book are available in all areas.

Living with dementia

People with dementia can have a good quality of life with help, support and quality care. Dementia is not just about memory loss. Many other problems can occur during the course of the illness including anxiety, depression, wandering, incontinence and aggression. These can be helped too, and we have included practical advice to help cope with the day-to-day problems that can occur in dementia.

Throughout this book we have used examples to illustrate some of the problems and difficulties. Although these are based on real patients, we have changed the details to ensure anonymity.

KEY POINTS

- The term 'dementia' is used to describe the symptoms that occur when the brain is affected by specific diseases and conditions
- Dementia is not part of normal ageing
- Dementia is common, affecting almost 700,000 people in the UK

What is dementia?

Case study – Mary

Mary, a retired factory worker, is 79 and lives alone after her husband died 3 years ago. Mary is becoming increasingly worried about her memory. Recently she went shopping and left her shopping trolley in the library when she popped in to return a book. On another occasion she forgot her PIN number when collecting her pension from the post office.

She visited her doctor because she thought she was developing Alzheimer's disease. Dr Thomas listened carefully to her problems and ordered some tests. It turned out Mary did not have dementia. 'As we get older our memory does get worse,' Dr Thomas told her. 'But a problem with memory alone does not mean someone is developing Alzheimer's disease, or any other dementia.'

This chapter explains what dementia is, and outlines the common types of dementia and conditions that can mimic it.

Defining dementia

Dementia is a term that is applied to several different conditions that affect the brain. Just like the word 'arthritis' refers to many different causes of joint pain, there are several different types of dementia, with subtly different symptoms. The most common cause of dementia is Alzheimer's disease, but there are many other causes.

Most kinds of dementia have similar symptoms including:

- Loss of memory
- Problems with thinking and planning
- Difficulties with language
- Failure to recognise people or objects
- A change of personality.

Our brains (if we think about what our brains do) have many different functions. Making a cup of tea might seem a simple task but in fact this is quite a complex task and provides examples of several different brain functions:

1. We imagine a cup of tea (**abstract thinking**) and decide to make one (**motivation**).
2. We may ask whoever is with us if they want a cup (**language**).
3. We plan making the tea ensuring that things are done in the right order, putting the tea in before the boiling water (**executive function**).
4. We remember where the tea, sugar and milk are stored (**memory**).

5. We put the kettle on and gather the ingredients (motor function).
6. We listen for the kettle (hearing), ensuring that we don't get distracted with some other task (attention and concentration).
7. We carefully pour (coordination) just the right amount of water (judgement) on to the tea.
8. We may then may add milk and sugar to the cup, in the right order (planning).
9. We wait until it has cooled sufficiently (judgement) and we enjoy the tea (taste).
10. All the way through we have probably spoken and acted in a similar manner to how we usually do (personality).

Most people reading this book have, at some time or another, made a mistake when making tea. For example, putting tea bags in the fridge and milk in the cupboard instead of the other way round, popping into the next room to ask someone if they want a cuppa and totally forgetting what you wanted to ask or making a cup of tea and forgetting to drink it.

This does not mean that you have dementia. When someone has dementia, usually several of the different brain functions outlined above begin to go wrong, and not just once but repeatedly over time.

So dementia could be defined as:

Persistent, progressive problems with more than one aspect of brain function (such as language, planning, motivation, memory or personality).

The *International Classification of Diseases* defines dementia as follows: each of the following, present for at least six months in someone who has no impairment of consciousness:

- Decline in memory
- Decline in other cognitive abilities such as judgement, thinking, planning
- Decline in emotional control (for example, irritability) or motivation.

Symptoms of dementia

In many types of dementia, problems with memory and complex thinking are the first symptoms. The memory loss is usually for recent things. So someone may have a clear recollection for things that happened years ago, but cannot remember things that happened a few hours or days ago.

Dementia must be differentiated from acute (sudden-onset) causes of confusion. Dementia comes on over months or years; if someone becomes confused over a matter of hours or days this is unlikely to be a dementia.

Acute confusion is usually the result of another physical cause such as:

- Infection (for example, chest or urine infection)
- A reaction to medicines
- Pain or constipation
- Stroke
- Other physical cause.

Having dementia is a risk factor for getting a more acute confusional state, but, in every case, if someone gets suddenly confused (or more confused), he or she should see a doctor to try to find the cause of the acute confusion.

People who have dementia can also become more confused if there is a change in routine, such as going on holiday or going into hospital.

Types of dementia

There are a large number of different types and causes of dementia but the great majority of people have one of four types:

1. Alzheimer's disease
2. Vascular dementia
3. Lewy body dementia
4. Frontotemporal dementia.

We shall concentrate on these four. Together, Alzheimer's disease and vascular dementia cause about 90 per cent of all cases of dementia.

Brain scans and special tests of brain function (cognitive tests) may help doctors tell what type of dementia a person has. However, the only sure way of telling what type of dementia is present is by doing a brain biopsy (removing a small piece of brain tissue and looking at it under a microscope). This is very rarely done.

Alzheimer's disease

Case study – Gordon

Gordon was 74 when his wife, Liz, first began to notice something was wrong. Looking back, Liz first noticed

that Gordon was not looking after his allotment properly. He had been a very keen gardener, often winning prizes for his vegetables. However, recently Gordon had made some mistakes: planting seeds at the wrong time, forgetting to water his plants and letting the weeds get out of control. Neighbours commented that his allotment was a mess.

At first Liz thought Gordon was just bored with gardening, but then other things happened. Gordon was driving back from the supermarket when he suddenly took a wrong turn and went the wrong way up a one-way street.

A few weeks later he got into a muddle with his bank statement and flew into a rage – a very rare thing for him to do.

Liz tried to get Gordon to see the doctor but he was adamant that there was nothing wrong. Eventually Liz called Dr Blunt herself, but he told her it was probably just old age and advised her not to worry.

Over the next year things got worse. Gordon began to dress less smartly, sometimes wearing the same clothes until Liz reminded him to change. He began to repeat conversations and would often ask Liz the same question several times over.

He gave up the allotment and would sit for hours doing very little. Liz insisted Gordon went to the doctor and this time she went with him and the doctor took a careful history of Gordon's problems and referred Gordon to the local memory assessment service.

After visiting Gordon and Liz at home and doing some tests, the consultant diagnosed Gordon as having Alzheimer's disease.

Alzheimer's disease is the most common form of dementia; about two-thirds of people with dementia have Alzheimer's disease. This disease was first described over 100 years ago by Alois Alzheimer who reported on a condition in a woman in her 50s. His description shows the range of symptoms that may develop in this condition:

One of the first disease symptoms of a 51-year-old woman was a strong feeling of jealousy towards her husband. Very soon she showed rapidly increasing memory impairments; she could not find her way about her home, she dragged objects to and fro, hid herself, or sometimes thought that people were out to kill her; then she would start to scream loudly. From time to time she was completely delirious, dragging her blankets and sheets to and fro, calling for her husband and daughter, and seeming to have auditory hallucinations. Often she would scream for hours and hours in a horrible voice.



Portrait of Alois Alzheimer 1864–1915

Alzheimer's disease usually begins with very mild symptoms. The first symptoms are often mild memory loss, which can be difficult to tell from normal forgetfulness as a result of getting older.

Mild confusion (for example, with managing bills) and problems with use of language may also be present early in the illness. Alzheimer's disease usually starts slowly and with very mild symptoms; it is rare to find someone where the onset can be dated to a particular time, and someone may have the condition for a year or two before it is diagnosed.

Alzheimer's disease also tends to progress slowly. As the disease gets worse, people may have a range of different symptoms (see page 33) and may eventually become very disabled, needing round-the-clock help.

What happens to the brain in Alzheimer's disease?

Scientists now know quite a lot about what happens to the brains of people with Alzheimer's disease. The brain is made up of millions of nerve cells (among other things), which enable us to think and remember.

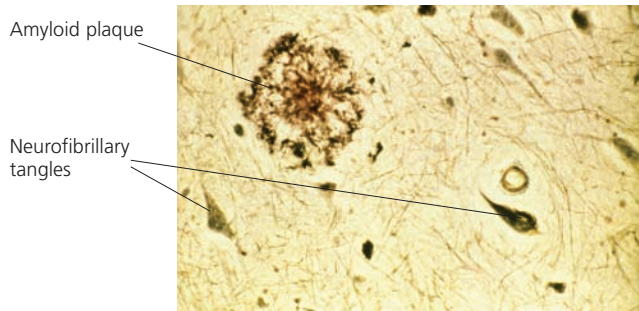
In a brain affected by Alzheimer's disease an abnormal protein called amyloid is made (for reasons that are not fully understood). Microscopic amounts of this amyloid protein are laid down in the outer layers of the brain in clumps called plaques.

These plaques are thought to affect the health of nerve cells or neurons. Neurons contain a protein called tau, which is involved in maintaining the shape of the nerve cell. Affected neurons begin to make an abnormal form of tau. This abnormal form of tau is thought to result in a change in structure of the cells.

Some nerve cells die and collapse in on themselves, creating clumps called tangles. These tangles, and the

Brain tissue under the microscope

Brain tissue affected by Alzheimer's disease showing tangles and plaques.



plaques of amyloid protein, are visible under the microscope and are the hallmarks of Alzheimer's disease.

Certain parts of the brain, especially the temporal lobe (a part of the brain where memory is stored) shrink as a result of the death of neurons. This shrinkage can be seen on some brain scans, and this can help doctors make a diagnosis.

The nerve cells in the brain communicate with each other using chemicals called transmitters. In Alzheimer's disease, there is less of some of these transmitters, and some treatments for Alzheimer's disease are aimed at increasing the levels of these chemicals (see 'Treatments for dementia', page 50).

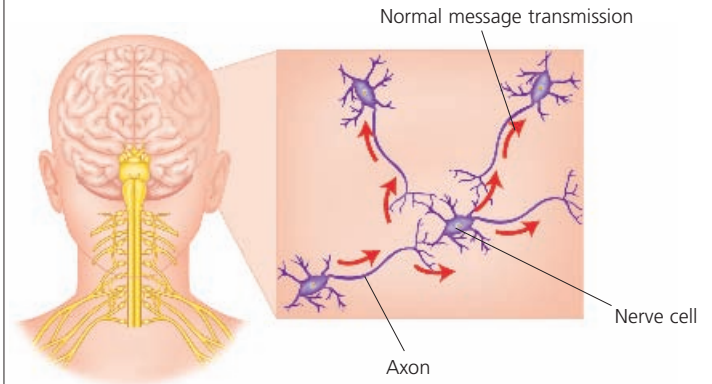
What causes Alzheimer's disease?

Little is known about what triggers the process that leads people to develop Alzheimer's disease. Alzheimer's disease may run in families, but this is

The process of Alzheimer's disease

1. Normal brain

Neurons within the brain transmit electrical messages to other parts of the body using chemicals called transmitters.



2. Brain with Alzheimer's disease

In Alzheimer's disease areas of the brain tissue are damaged and this interferes with message transmission, causing the symptoms of the disease.

