

# Dementia: The One-Stop Guide

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# Dementia: The One-Stop Guide

*Practical advice for families, professionals and people  
living with dementia and Alzheimer's disease*

Professor June Andrews

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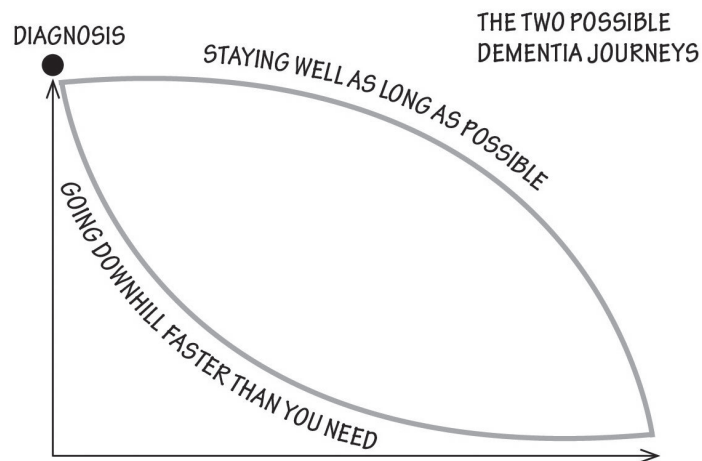
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# Introduction



This book is all about dementia and what happens when someone is affected by it. The word 'dementia' is used to describe the collection of warning signs that show up when your brain stops working as well as it used to. It is defined as dementia only if these signs continue to get worse, with a permanent deterioration over time. If you know about dementia you will be better able to look after yourself or someone in your family who is affected by it.

Interest in dementia in the media has never been so great. Films have been made about famous people who had dementia. *Iris*, starring Dame Judi Dench, tells the true story of the English novelist Iris Murdoch from her brilliant youth to her last days in a care home. *The Iron Lady* is a moving film which explores Margaret Thatcher's life through fragments of history that represent her disintegrating thinking and recollection clouded by dementia (and some rather impressive hallucinations). Movies also explore ethical issues of caring. *Away from Her* and *The Savages* describe the caring dilemmas of a husband in one case and children in the other. Although there is still stigma, this public airing means that people are more open about dementia and allow themselves to think about it more than they did in the past. This is all good.

Public figures affected by dementia in their families are recruited as champions by dementia charities and encouraged to talk publicly about dementia and share their stories with other people. Often when I get into a taxi and the driver asks me what I do, I hear a personal story about how dementia has affected their family. Once upon a time it was a shameful secret.

Nevertheless, it is almost impossible to get sensible advice about dementia. We are faced with waves of publicity on the subject as newspapers print misleading headlines implying that there will be miracle cures available almost immediately. Families affected by dementia live in fear of losing their entire life's savings in care home fees. Television adverts encourage us to be positive about dementia while at the same time

celebrities and thought leaders say that they'd rather have cancer, or that they believe they'd have a duty to kill themselves if they had dementia. Investigative reporters make TV shows out of the misery of vulnerable people who have been on the receiving end of bad care. Scandalous nursing-home stories ruin our confidence that there might be a nursing home anywhere in which residents, even if they deteriorate, have the benefit of comfort and good cheer. The often-reported heartbreaking treatment of patients with dementia in hospital makes us afraid for ourselves and our older relatives.

In the middle of all this, thousands of people every year get the shocking news that someone in their family has dementia. For many of them their experience unfolds as if no one has ever travelled this path before. They are in uncharted territory, often surrounded by health and social care workers who don't know a huge amount about the condition. For many people it is hard to know where to turn for sensible advice.

How do I know this? In 2011, with Professor Allan House, a liaison psychiatrist, I wrote a book in plain language called '10 Helpful Hints for Carers' based on the existing research. Our printers' proof copies kept being 'borrowed' by doctors, who did not return them. When it was published, families read it avidly. Within two years over 30,000 copies had been sold, or exchanged for donations for the Dementia Services Development Trust, the charity that supported us. Families said, 'Why did no one ever tell us these things before?' Health and social care workers and volunteers took more and more

copies, to give to patients, to families and to fellow workers who had never been taught about dementia in their training. At last there was some sensible and practical advice for anyone trying to make things better for people with dementia. But it was not enough. This book gives more information and advice about how to cope with the dementia journey the best way you can.

Everyone has a unique experience, but in general there are two possible routes with dementia. On one track you stay as well as possible for as long as possible, living life the way you want to. On the other you go downhill faster than you need to, for reasons that are often avoidable. Everyone would like to avoid unnecessary trouble and expense, and to delay some of the difficult situations that might arise. Sensible, practical advice on how to do this is in short supply. People aren't told about the remarkable services and equipment that are readily available or the simple changes to their lifestyle that can be so radical that they prevent the need to go into a care home.

*The One-Stop Guide to Dementia* provides detailed information about what will make a difference in the lives of people with dementia and their carers. It is practical and compact, and builds on the '10 Helpful Hints'. In setting out to write this, I've drawn on information that is freely available if you've got a clinical qualification that prepares you to understand it and a few months to research it. However, when someone in your family gets dementia you may not have that sort of time. This book is for you.



## chapter 1

# *What is dementia?*

People use the term dementia to mean a number of things. This chapter will give you a basic understanding of the commonest types of dementia and why it is useful to know the difference between them for practical reasons. Dementia is much more than just a memory problem and you might find that some of the professionals you meet are misinformed about it, so the more you know the better.

A range of diseases can cause the changes in the brain that give rise to dementia symptoms. There are probably more than a hundred of these diseases, but three or four of them are very common. The commonest is Alzheimer's disease. Up until recently student doctors and nurses were told little if anything about dementia. And if they were told anything, it was often wrong. They were told not to worry about what underlying ailment was causing the patient to have the dementia signs and symptoms. This way of thinking was known by real experts to be wrong long before it was ever corrected in the education of the professionals. People were misinformed. It was lazy thinking, which was inexcusable, even though there was not enough research on the subject.

What did they used to say in the past? In my own experience I've heard all of these misleading statements ... and there are more:

- ◆ It's just a memory problem.
- ◆ We shouldn't worry patients about this because we can't be sure of the diagnosis.
- ◆ You can't really tell for sure what disease is causing the problem until the post-mortem, so that limits what you can do for them.
- ◆ There is no point in raising the question of an underlying disease with the patient or their family because there is nothing that can be done.
- ◆ The treatment is the same no matter what the cause, so even the doctors and nurses don't need to distinguish between the possible causes of dementia.
- ◆ It's part of normal ageing – you expect and accept these symptoms in old people.
- ◆ It's a wasting disease – you can expect them to lose weight and die quite quickly.

In the course of this chapter I'll show that all of these assertions are wrong, but you need to be aware that this is what was taught to very many of the doctors, nurses, social workers and others you might meet. You'll end up knowing more than they do. But you have to work with these people, so how you handle that difference in your level of knowledge can be tricky. The situation is getting better with all the recent public interest in dementia, but research shows that even if the professionals who are now working in the health and social

care system received any dementia education in their undergraduate or pre-registration training, it was more likely to be about the anatomy and physiology of the declining brain tissue than about answers to practical questions, like what you should do if the person starts getting lost in the night. I hesitate to say that it was useless, but certainly the education has not been good enough from the point of view of carers or people with dementia who come to professionals looking for help. Most of the people with dementia seen by students in the past were in hospital and largely unable to do even the most basic tasks, and often they were behaving in very disturbing ways. That's how medical people viewed dementia – they expected dramatic and painful debilitation and chaos. They never realised that 75 per cent of people with dementia were living quietly at home.

Things are a bit better now. There is a lot of publicity and more education. All the people who have been formally diagnosed with dementia are listed on a register at their GP's surgery, so that they can be considered for help, treatment and support. (At least they should be ... in some cases the clinic doing the diagnosis fails to communicate it to the GP.) Their carer is given a right to support through this mechanism. The Health Departments in the UK provide an incentive to family doctors by giving them an extra payment for putting people on the register. So that's good. What's more, many people are getting their diagnosis (if they get a diagnosis) at earlier stages of the condition, when they still have a lot of independence and can enjoy life, exercising their capacity to make decisions and have fun.

That early diagnosis also means that they have more potential benefit from the limited range of medication that is available and can plan their future better.

But when you ask the question 'Is this dementia?' you are still dependent on a doctor to put a name to the troubling symptoms that have beset you or your loved one. If the doctor remembers his or her training and it was as bad as mine was, they'll not feel confident enough to make a diagnosis, and might still believe there is no point in trying. This means that you might have to push for that diagnosis. There is huge variation across the UK. At the time of writing, in Scotland and Northern Ireland two-thirds to three-quarters of the people with dementia symptoms will have been formally diagnosed. In some parts of England as few as 20 per cent of the people with dementia symptoms get their diagnosis. In total on average across all of England it is less than half at the time of writing.

Particularly when they are older or if someone in their family has had dementia, people worry about whether they themselves are getting dementia. It's all over the news, and in surveys the majority of respondents say they'd rather have cancer, so it is clearly terrifying. Sometimes people who think they have it try to hide it. Couples collude with each other, pretending that everything is all right when it isn't. Children worry about their parents and may be fearful of raising the subject. Friends don't like to mention it in case they cause offence. That's understandable, but there is no justification for any doctors to still actively avoid addressing the issue, though they clearly do.

What can you – as families and patients – do, given all the rules about patient confidentiality, if you have difficulty getting a GP to take your concerns seriously? The first step is to find out for yourself as much as you can about dementia and the associated problems. That will give you power.

## Things that look like dementia but aren't

### *Mild cognitive impairment*

There is a condition called mild cognitive impairment (MCI), which many of us will get if we are lucky enough to grow old. Because some people who get dementia start with MCI it can be very worrying to have it. But cheer up! Studies show that the majority of individuals with this memory loss never progress to having full-blown dementia, and MCI itself can sometimes be reversed or at least remain stable. You need to know what to do about MCI and how not to worry, but you also need to be sure to see a doctor if you really think it is progressing to become dementia.

If you have MCI you may have minor difficulties with memory and attention, and some language issues. It is like being mentally tired all the time. In fact it can be brought on by stress and fatigue, or another illness, but unlike dementia it is potentially reversible and not necessarily progressive.

People with MCI have problems that are less extreme than people with dementia. At least 5 per cent of older people have MCI, depending on how you define it. It would be really useful if you could tell which of those

are going to go on to develop dementia, but at present there is no real way of knowing, so that means there is a limit to what doctors can do. There is some evidence that brain exercises might help, and all the things that you will read about later in this book that help reduce dementia symptoms are probably sensible to consider as a precaution in MCI.

### *Delirium*

Another condition, called delirium, is a fluctuating temporary confusion that often happens to older people when they are ill because of something else, such as a urine infection, or too many pills, or a chest infection. Delirium can be dangerous if it is not treated and people die as a result. Sometimes it is an early sign that the person is likely to get dementia in years to come, so if you've had it your GP needs to be told. If delirium occurs in hospital, it may not get treated because staff see the older person in bed being 'confused' and don't think there is anything abnormal with that. As is made clear in Chapter 12, you need to make sure medical and nursing staff know if the level of confusion is a change and a deterioration from how the person usually is and you need to persuade the doctors and nurses to treat the cause.

### *Depression*

In addition, if an older person gets depression, that may look a lot like dementia. Fortunately, depression can be treated and reversed. It is tragic if the health care staff wrongly assume that it is dementia and that nothing can