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Chapter 1

About dementia

If someone close to you has been given a diagnosis of dementia you are likely to be going through a range of emotions. Some people find themselves wanting to find out all they can – others would rather not know more than the bare facts. This chapter tells you about dementia and has been written in such a way that, if you like, you can just read the short headings and get the minimum of information. If, on the other hand, you would like to understand much more, you can read the whole chapter thoroughly and then do your own further research.

Even if you prefer not to know everything at this stage, I recommend that you read the short paragraphs in bold: this will help your understanding and mean that you can care for the person with the diagnosis as well as possible.

What do we mean by ‘dementia’?

The word dementia is an umbrella term that covers a number of neurological degenerative conditions including Alzheimer’s disease, vascular dementia and fronto-temporal dementia.

Given the ‘D’ word is one that frightens people a lot, it is important we understand what it means. Sometimes the popular press seems to have a problem separating ‘dementia’ from Alzheimer’s disease. Dementia is a word that describes the symptoms that





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develop in a number of different diseases. There are thought to be more than 200 types of dementia and Alzheimer's disease is only one of them, although it is believed to be the most common, affecting rather more than half of those with symptoms of dementia. The next most common form of dementia is thought to be vascular dementia.

Dementia with Lewy bodies (or Lewy body dementia) and fronto-temporal dementia are two other types. The term 'fronto-temporal dementia' is in itself used to describe a range of conditions, including Pick's disease, frontal lobe degeneration and the dementia associated with motor neurone disease, where damage occurs in the frontal or temporal lobe areas of the brain, or both.

There are many other rarer causes of dementia. Dementia may also occur as a result of other specific diseases (for example, in Huntington's disease). These will not be covered in any detail in this book.

You may also hear the term **mild cognitive impairment (MCI)**. This is not dementia but rather a condition where someone may have some of the features of dementia (mainly memory problems – see below) but the person affected is able to function in their daily life (see also pages 9–10). It is thought that people with MCI have a higher risk of developing dementia later on.

Dementia, therefore, can be described as a collection of symptoms, including memory loss, perceived personality change, and impaired intellectual functions resulting from degenerative disease or trauma to the brain. These changes are not part of normal ageing and they are severe enough to impact daily living, independence and relationships. This book is about coping with dementia, whatever its cause, as the long-term challenges are the same, as I describe later in this chapter. It is, however, principally about dementia caused by Alzheimer's disease, vascular dementia, dementia with Lewy bodies and fronto-lobal dementia. Much that I have included is relevant to rarer causes but I do not look at these specifically.





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What is the difference between dementia and normal ageing?

With dementia, someone is likely to show a noticeable decline in the ability to communicate, to learn skills, to remember things and to solve problems – what is known as ‘executive function’.

These changes may occur quickly or very slowly over time. If you think someone may have dementia you may have noticed some or all of the following:

- Short-term memory loss
- Impaired judgement
- Difficulties with abstract thinking
- Faulty reasoning
- Inappropriate behaviour
- Loss of communication skills
- Disorientation in time and place
- Gait, motor and balance problems
- Neglect of personal care and safety
- Hallucinations, abnormal beliefs, anxiety, agitation.

My mother-in-law suddenly became very frightened of being alone in the house. She double-locked all the doors, which at first we thought a sensible precaution. But later we found she had put chairs under the door handles as well, to prevent them being opened and she started getting very worried when we left the house and began ringing us up at all hours to check where we were.

The fact is that, as we grow older, many of us suffer from some of the above symptoms. It is very difficult for someone without medical knowledge to know whether these are a sign of ‘normal’





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ageing or are evidence of developing dementia. It can be very frightening to forget your telephone number or a recent event and then to worry that you are developing dementia.

Looking back I remember when our first grandchild was born – a boy. We were both delighted but for some reason my husband kept referring to the baby as ‘she’ – even though he was called Michael. I dismissed it as a slip of the tongue at the time, although he kept on doing it. Now I wonder if that was the first ‘sign’.

Dementia is not part of normal ageing. Older people may have memory lapses but the memory problems associated with dementia are specific to the illness.

Losing your thread

It is possible to compare some of the symptoms and to see how these differ in normal ageing and in dementia. For example, any elderly (or not so elderly) person may complain about memory loss, but on questioning they would be able to provide examples of this, such as ‘I completely forgot where I put my keys yesterday.’ However, someone with dementia may not even realise that they have memory problems, may indeed vigorously deny this and may accuse others of making things up when they are given examples of how they have forgotten something.

Most people have occasions when they have to search for a word or substitute a word temporarily. Someone with dementia frequently has to pause to find the right word and may often lose their way in a sentence, perhaps trailing off or diverting to some other subject or drifting into irrelevance.





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I noticed my sister would lose track of herself in the middle of a sentence. We had always had very lively discussions about many subjects but she started losing the thread of an argument. If I prompted her she would make an excuse and say I was distracting her or that she couldn't be bothered to talk because she was tired.

Getting lost in familiar places

As we get older some of us may find we have to pause to recall directions clearly or may have to repeat directions to remember them, but we do not get lost in familiar places or forget the route home from the local shops, for example. People with dementia may often get lost in familiar places. Many carers say one of the first things they noticed was that the person with dementia forgot a simple route, such as the way back from the toilet in a restaurant (this is a very good example of short-term memory loss).

Forgetting what just happened

Older people generally can remember recent personal events, especially major events, but people with dementia may forget what happened yesterday even if it was something as important as a grandchild's christening. They may, however, easily recall events in the distant past with great clarity.

My father kept accusing us of neglecting him and not coming to see him. If I pointed out that we had come to see him the day before, he would strongly deny this and even get abusive. Sometimes I could convince him by showing something I had





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brought with me on a previous visit but often he would accuse me of tricking him or 'planting the evidence' just to catch him out.

Losing interest

People with dementia may lose interest in social activities or hobbies and pastimes. They may forget to wash or be unable to put on a simple article of clothing.

Older people generally retain their social skills and normal routines, such as washing and dressing, even if it takes them longer to carry out these actions than when they were younger. They also usually continue to enjoy social occasions and their normal interests.

The first thing I recall noticing was that he stopped going fishing. Previously it had been his favourite hobby. He often talked about going but he didn't actually do anything. If I asked him about it he usually had an excuse – he was busy, or something had come up that was more important. It was only much later that I looked back and saw that as the first sign.

What else might it be?

These signs and symptoms are indicative of dementia, but we have to be wary of making assumptions. For example, some forms of **depression** cause people to lose interest in their appearance and to cease bothering to wash or change their clothes. There are also a number of conditions that may 'mimic' dementia or cause a temporary dementia-like state. One example is **low blood sugar**, which can cause susceptible people to become confused and agitated. A **urinary infection**





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can also cause symptoms similar to dementia in older people. These symptoms normally come on fairly suddenly, without the history of a slow decline that we usually see with developing dementia.

WHY ME?

We do not know the cause(s) of dementia but we understand what some of the risk factors are. Having a number of risk factors may make you more likely to develop dementia.

We do not know an absolute 'cause' of dementia. Research seems to indicate that, as with many diseases, there is no one cause, but there are a number of 'risk factors' which might increase the risk of dementia developing in any one person.

It is believed that the risk of developing dementia is affected by a combination of genetic and environmental factors. This suggests that everyone is at risk of developing dementia but some are more at risk than others. Because a specific cause is not known it is also true to say that we do not know what factors do not cause dementia. However, research indicates that it is not a contagious disease – that is, you cannot 'catch' dementia from being with someone who develops the disease.

Age as a risk factor

It is important to remember that dementia is NOT a normal symptom of ageing. However, age is the most significant known risk factor for dementia. It is possible to develop dementia early in life (early-onset dementia), but the chances of developing it increase significantly as we get older. One in 50 people between the ages of 65 and 70 has some form of dementia, compared with one in five people over the age of 80.

Other risk factors include uncontrolled or poorly controlled





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diabetes, past injuries to the head, genetic makeup, and some other specific medical conditions.

Genetic risk factors for early-onset dementia

Certain genes can affect a person's risk of developing Alzheimer's disease specifically, although our knowledge about this is incomplete. **The evidence of a genetic cause is stronger for early-onset dementia.**

The three genes that have a major effect on the risk of developing early-onset Alzheimer's disease are, for those who want the detail, the amyloid precursor protein (APP) gene and two presenilin genes (PSEN-1 and PSEN-2). People with abnormalities in these genes can develop the disease in their 30s or 40s, and usually come from families in which several members also have early-onset Alzheimer's disease.

Genetic mutations on these three genes are very rare: they account for fewer than one in 1,000 cases of Alzheimer's disease.

It is believed that everyone who inherits a genetic defect in any one of the three genes will develop Alzheimer's disease at a comparatively early age. And, on average, half of the children of a person with one of these rare genetic defects will inherit the disease. Those who do not inherit the defective genes cannot pass it on.

If you have two or more close relatives (a close relative is defined as a parent or sibling) who developed Alzheimer's disease before the age of 60, you could ask your doctor to advise you about genetic counselling and testing.

Genetic risks for late-onset dementia

With late-onset dementia, the genetics are not so clear. For example, a gene called apolipoprotein E (ApoE) has been shown to play a part in the development of late-onset Alzheimer's disease





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and possibly also in vascular dementia. The effects of various combinations of the ApoE gene seem to be subtle and, although it is not believed that the gene directly causes Alzheimer's, the variations seem to increase or decrease the risk of developing the disease.

As research on the genetics of Alzheimer's disease progresses, researchers are uncovering links between late-onset Alzheimer's and a number of other genes, including CLU, PICALM, CR1, BIN1, ABCA7, MS4A, CD33, EPHA1 and CD2AP. These genes appear to have a much smaller effect than ApoE on the risk of developing Alzheimer's disease, but research has shown that they may be significant. Research to find further genes which increase the risk or have a protective effect is very much ongoing and it is possible that new information about genes linked to dementia will in time give us a better understanding of the biological mechanisms and potential future treatments for dementia.

'Mild cognitive impairment' as a risk factor

Mild cognitive impairment (MCI) is not dementia, but anyone with MCI is more likely to develop dementia.

MCI is a relatively new expression in medical terminology. It is a descriptive term rather than a specific medical condition or disease and describes the memory loss that the sufferer – and those around them – will have become aware of. Formal memory tests may highlight this memory loss but the person will not have any other symptoms of dementia.

People with MCI usually have impaired memory or mild impairments in other areas of brain function, such as planning or attention span, but do not experience significant problems in carrying out the functions of everyday living.

It is thought that people who have MCI are at an increased risk





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of going on to develop Alzheimer's disease or another form of dementia. The Alzheimer's Society states that: 'In studies carried out in memory clinics, 10–15 per cent of people with MCI went on to develop dementia in each year that the research results were followed up. In community studies and clinical trials the rates are about half this level, but MCI still represents a significantly increased level of risk.'

However, many people with MCI improve or remain stable and do not develop dementia.

There are other 'lifestyle factors' that may increase the risk of developing dementia. These are covered extensively in my book *The Essential Guide to Avoiding Dementia* and are also described in chapter 9.

WHAT CAN I EXPECT?

Dementia progresses differently in different people but it is a progressive disease: the symptoms will become worse over time. There is no known cure.

The progression and outcome of dementia vary from person to person, but are largely determined by the type of dementia and which area of the brain is affected. The popular press usually emphasises the loss of short-term memory, but, although this is a classic symptom, it may not be the first sign that arouses anxiety in those developing dementia or their family. This emphasis on short-term memory may mean that people do not realise that other signs and symptoms may be more important in terms of indicating cognitive decline.

For convenience doctors sometimes talk about the 'stages' of dementia. This is a bit misleading as dementia does not progress in a standard way, but varies with each individual. Here is one view of the generally accepted stages of dementia:





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Early dementia – In so-called ‘early dementia’, there are clear-cut deficits on careful clinical interview. For example, there might be difficulty performing complex tasks, such as handling finances, or travelling. Denial is common. There may be withdrawal from challenging situations. Someone with early dementia might be able to live independently – perhaps with assistance from family or caregivers.

Moderate dementia – People with ‘moderate dementia’ cannot survive alone without some assistance. They will be unable to recall major relevant aspects of their current lives, such as an address or telephone number of many years, or the names of grandchildren. There will be some disorientation as to the date, day of the week, season, or to place. They will probably require little assistance with toileting, eating, or dressing, but may need help choosing appropriate clothing. They generally live at home with live-in family members or other home support.

Moderately severe dementia – In ‘moderately severe dementia’, sufferers may occasionally forget the name of their spouse. They will be largely unaware of recent experiences and events in their lives. They will require assistance with basic activities of daily living (‘ADLs’) and they may be incontinent of urine. Behavioural and psychological symptoms of dementia (‘BPSD’ – see page 130) are common, such as delusions, repetitive behaviours and agitation. At this stage they may need to live in a residential care home.

Severe dementia – In reaching this stage, sufferers will have lost their verbal abilities – that is, their ability to use words. They will also have lost their ability to walk. They will be doubly incontinent and need assistance with feeding.





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In fact everyone differs in the way their dementia progresses. Some people may lose the ability to speak in coherent sentences early on and this may be the prompt which causes them (or relatives on their behalf) to seek diagnosis. Loss of this ability may result in long pauses between words, or it may cause increasing silences and refusal to engage in normal social conversation. On the other hand, the person with dementia may continue to speak fluently for a long time but their sentences become confused and muddled and they may seem incoherent to those trying to talk to them.

Sometimes the ability to write is lost early on, although coherent speech is retained. Some people may notice that they are no longer able to sign their name. Interestingly, the ability to read (although not necessarily with comprehension) is often retained for many years after the onset of dementia.

Increasing inability to follow a sequence when performing common activities may be one of the first signs that there is something wrong. The person with dementia may find it difficult to put their clothes on in the right order, or to make a cup of tea, or to follow a recipe. These are actions we all perform for years almost automatically and so when this ability is lost it generally causes great consternation, prompting people to visit their doctor to seek a diagnosis.

The first indication that there was anything wrong was when my wife found herself in a muddle when cooking. She had always been a great baker of cakes, but suddenly it seemed she couldn't understand the recipe and there were several 'disasters' which ended with her in tears before I persuaded her to see the doctor. To be honest, I thought it might be something wrong with her sight so the diagnosis was a bit of a shock.





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In common with the loss of ability to follow a sequence, loss of orientation may also alert family and friends that all is not well. Sometimes one of the first signs is 'getting lost' in a familiar environment or forgetting a commonly used route, such as the way to the local shops. In some cases, lack of orientation can be one of the biggest problems: the person with developing dementia can still hold conversations, carry out common tasks and continue to read and write, but they have difficulty finding their way about.

My wife started accusing me of hitting the ball in the wrong direction when we played a game of golf. I didn't realise what she meant at first but within quite a short time I found no one would play with me because I had no idea which way to face when playing. Not long after that I turned the wrong way when leaving the pub one night to walk home and if a friend had not chased after me I would have got hopelessly lost, even though I only lived half a mile away.

Initially the person with dementia is able to cope with normal activities provided they are not over-stressed. Difficulties may happen only occasionally and may be written off by family and friends as the natural 'slowing down' of increasing age. Lapses of memory may be covered up or go unnoticed; difficulties with following a television programme or the plot of a film passed off as due to tiredness. Practical problems with following a sequence of actions (dressing or following a recipe) can initially be overcome by taking more time or by preparation such as laying clothes out the night before. With help and regular support and care, the person with dementia can have a good quality of life, usually for some years.

The disease will progress over time (usually a few years) and there is no known cure. Medication can sometimes stabilise





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people for a while but (for reasons which are not completely understood) the medication becomes less effective and people with dementia will find that their capabilities deteriorate and their ability to manage life independently disappears. As a general rule, long-term residential care or intensive home support will be needed eventually.

The effects of different causes early on

Although the symptoms of dementia are often similar, the early physical effects of various dementias on the brain and the body are different.

Medical science has discovered how the disease manifests in the brain, but there is still a lack of knowledge about cause and effect.

In **Alzheimer's disease**, the two most common features are **plaques and tangles** in the brain. These were first described by Alois Alzheimer, after whom the disease was named. Plaques are small clumps of a protein known as beta-amyloid, which usually exists in the brain in a soluble form. With Alzheimer's disease the amyloid clumps together into solid deposits known as **plaques**. This disrupts the normal workings of the brain.

During the course of the disease, **tangles**, which look like dark shapes, develop within the cells of the brain. They are made up of a protein known as Tau. In a normal brain, Tau forms rope-like structures that guide chemical messages and brain nutrients down the axon (the long tail) of the cell to send messages on to other cells. With Alzheimer's disease an abnormal form of Tau accumulates that tangles up the rope-like structures. This causes brain cells to die from lack of nutrients. Patients with Alzheimer's also have a deficiency in the levels of some neurotransmitters – vital brain chemicals involved with the transmission of messages. Eventually the brain begins to atrophy. Alzheimer's disease tends to progress steadily with a slow decline in abilities.





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However, some elderly people have many of these plaques and tangles in their brain but they do not display signs of dementia, so this is not the whole story.

Vascular dementia develops where problems with blood circulation result in parts of the brain not receiving enough blood and oxygen. We know that this can cause small areas of the brain to 'die'. Although the human brain can compensate for this (as evidenced by the number of people who recover function after a stroke), if enough areas are damaged so that they can no longer function, the ability to carry out everyday tasks and to learn anything new will be lost. In vascular dementia, the progress of the disease is often 'stepped'. Any new incident (such as a tiny stroke) will cause an abrupt decline in abilities, followed by a period of stability until the next incident.

At the time of writing, medical opinion is changing. The thinking is that even with plaques and tangles present in the brain, Alzheimer's disease is unlikely to develop without some precipitating factor – most probably a small stroke. This may be small enough to go unnoticed initially, but the disease progresses. For this reason, many doctors now often diagnose 'mixed dementia' rather than specifying vascular dementia or Alzheimer's disease.

In **dementia with Lewy bodies**, abnormal structures, known as Lewy bodies, develop inside the brain. These are tiny, spherical protein deposits found in nerve cells. Their presence in the brain disrupts its normal functioning, interrupting the action of important chemical messengers, including acetylcholine and dopamine. Researchers have yet to understand fully why Lewy bodies occur in the brain and how they cause damage. Lewy bodies are also found in the brains of people with Parkinson's disease, a progressive neurological disease that affects movement. People who have dementia with Lewy bodies may experience detailed and convincing visual hallucinations (seeing things that are not there), often of people or animals. They are also inclined





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to fall asleep very easily by day, and have restless, disturbed nights with confusion, nightmares and hallucinations. They may have stiff movements and tremors, faint or fall over and their abilities are likely to fluctuate daily or even hourly.

In **fronto-temporal dementia**, the frontal and temporal lobes of the brain begin to shrink. Unlike other types of dementia, fronto-temporal dementia usually develops in people who are under 65. It is much rarer than other types of dementia. People with fronto-temporal dementia often find that their memory is not affected so early in the disease as with other forms of dementia. Instead, speech may be affected and the social inhibitions that help us to behave in a considerate manner to others may be lost.

Can dementia be treated?

The different types of dementia may cause different symptoms at first but all of them are progressive. At present there is no cure and only limited treatment for some types.

All bodily functions rely upon the brain to work and as the brain becomes less and less able to function, so the person with a dementing illness will become less and less able to carry out the functions of everyday living. Eventually a person with dementia will become unable to walk, to swallow, even to breathe. In actual fact, most people die of an infection or some other illness before this happens.

Medical treatment can help some people with dementia but it cannot cure dementia or stop its progress.

Treatment (where available) varies with different types of dementia and this is one reason why early diagnosis is so important. Another reason is that, as with any progressive terminal illness, knowledge of the future allows people to make plans and indicate their wishes while they are still able to do so.





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Drugs that may slow dementia's progress down

In Alzheimer's disease

Medication can improve symptoms, or temporarily slow down the progression of the disease in some people.

The key drugs used in cases of Alzheimer's disease are cholinesterase inhibitors and N-Methyl-D-aspartate (NMDA) receptor antagonists, which work in different ways. Cholinesterase inhibitors include donepezil hydrochloride (which you may know as 'Aricept'), rivastigmine (Exelon) and galantamine (Reminyl). The NMDA receptor antagonist is memantine (Ebixa).

Cholinesterase inhibitors do not work for everyone. Between 40 and 70 per cent of people with Alzheimer's disease benefit from cholinesterase inhibitor treatment but symptoms may improve only temporarily, for between six months and a couple of years in most cases. However, new research has indicated that even people with severe Alzheimer's disease may benefit from their use. People taking the drugs have experienced improvements in motivation, anxiety levels and confidence, as well as increased ability to deal with the tasks of daily living, and improved memory and thinking ability. Some people have claimed that the effect is 'like a miracle', while others notice no benefit. Identifying who will benefit can be difficult.

Memantine is licensed for the treatment of moderate-to-severe Alzheimer's disease. It can temporarily slow down the progression of symptoms, including loss of everyday functions, in people in the middle and later stages of the disease. There is evidence that memantine may also help with symptoms such as aggression and agitation.

In vascular dementia

Trials examining **cholinesterase inhibitors** for the treatment of **vascular dementia** indicate that the benefits for this type of dementia are very modest, except in individuals with a combination





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of both Alzheimer's disease and vascular dementia. Treatment for vascular dementia is usually concentrated on preventing further vascular problems and may include medication for stroke, high blood pressure, diabetes and heart problems.

In dementia with Lewy bodies

There is some evidence that the medications used for Alzheimer's disease are also effective for those who have **dementia with Lewy bodies**. People who are experiencing symptoms such as rigidity and stiffness may benefit from drugs used to treat Parkinson's disease, although these can make hallucinations and confusion worse. For people with dementia with Lewy bodies, neuroleptics (strong tranquillisers usually given to people with severe mental health problems) may be particularly dangerous.

In fronto-temporal dementia

The drugs used for treatment of Alzheimer's disease do not work for **fronto-temporal dementia** and indeed may make symptoms worse. Treatment is based around support and therapy (such as speech and language therapy).

WHAT ELSE CAN I DO?

There are lots of ways for people with dementia and their carers to help themselves – this book is one source of help.

Much of the treatment for dementia is centred around support for both people with dementia and their carers. Community psychiatric nurses, speech and language therapists, occupational therapists and dementia support workers can all get involved and show people with dementia how to manage their declining abilities. Carers, for example, can be taught strategies to manage challenging behaviour in those they care for.

People with dementia and those caring for them will need





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help to apply for relevant financial help and support, aids and appliances to help with daily living, and help to find suitable day-care facilities, respite care and long-term residential care as required. There is robust evidence to show that good support at home can delay the need for long-term residential care. The Alzheimer's Society is an excellent source of help and support and, in some areas, community mental health teams work with Alzheimer Society Dementia Support workers and Dementia Advisers to provide ongoing support to those who have been diagnosed with any form of dementia and to those who care for them.

Whatever else you do, read this book either in detail or just the highlights, and plan ahead. Denial does not help anyone and it stands in the way of seeking help.







Chapter 2

Build a team

When dementia takes hold you need outside support because, as people get worse, they cannot be left alone for any length of time and the carer needs to share the burden with others.

Why do you need a support team? When it comes to dementia you cannot 'go it alone'. It doesn't matter whether you are independent and used to managing your own affairs, that you're 'not a sociable person' or are used to 'keeping yourselves to yourselves'. You as a couple (carer and person with dementia) may pride yourselves on one, any, or all of these virtues, but it is important once dementia strikes that you re-think your attitudes.

People who have dementia cannot manage alone except for a very short time. Because they have problems with their memory sequencing, they may think – and they may assure you – that they can manage very well. This is because they have managed in the past and are remembering those times. As their memory and cognitive function are no longer working properly, they forget all the occasions when things haven't gone so well.

If you are caring for a parent who lives alone it may be very tempting to believe them when they say they can manage. It will not be true. If you are caring for a spouse or partner, it will be more obvious that they are not managing – but it may nevertheless take you a while to realise this.





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Couples who live together tend to support each other and sometimes increase that level of support without even realising they are doing so. It can be helpful to take a few moments to consider your life together now and how it was 10 years ago. Did your spouse/partner rely on you this much back then? If you are giving more support now (however subtly that level of support has increased) and if this is not due solely to physical disability, then their cognitive abilities have changed.

A person who has dementia can NOT live alone successfully, and in a perfect world we would never expect them to do so. 'Care packages' that involve carers calling in once, twice or even three times a day to help someone living alone are only a stop-gap measure. Very good carers who take pride in their work and genuinely care about their clients can make a difference, but they cannot replace the constant watchful presence that is required in all cases except the very early stages of dementia. Sometimes, however, this kind of care is the only and right option at the time and in this case it is important to get the very best care package that you can for as long as it is possible to manage this way.

On the other hand, spouses and partners who live with someone who has dementia are put under constant stress as they try to look after them. Living with another person – even when they are in good health – requires constant compromise as we adjust our habits, actions and conversation in the interests of 'rubbing along together'. Over many years these actions and adjustments become habitual, but they still remain. The most important thing to remember and take note of is that in any social situation all persons are involved in this constant compromise. Of course we can recognise that most partnerships are unequal and that one partner may make more adjustments than the other. Usually the person who makes more adjustments to the will of another does this willingly. Nevertheless, living with someone involves a constant daily compromise between pleasing ourselves and pleasing another. But people who have dementia gradually lose





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their ability to see another person's point of view – they lose their ability to empathise, to understand the everyday compromises that kept the partnership going. The partner who is the carer is left making all the compromises – possibly without even the satisfaction of a shared sense of humour or of togetherness – and certainly without the feelings of support they may have once had from their partner.

This is a burden that no one, however loving and dedicated, should carry alone.

If you are a carer in this situation, what can you do? You can build a team to help you.

WHO WILL BE ON YOUR TEAM?

Your support team can consist of anyone who is prepared to give time and help to you and the person you are caring for: family, friends, neighbours, professional carers, staff in a day centre and support workers from organisations such as the Alzheimer's Society can all be included.

Ask the family

It may be difficult to imagine family members as part of a support 'team' but most of us already rely on our family in many situations. There are many benefits to having members of the family as part of the team. The person you are caring for already knows them and feels comfortable with them. He/she will be used to their company and to their helping hand in some situations. Family members know the person with dementia from before the illness was diagnosed and these shared memories can be very important – as can the ability of family members to see beyond the dementia to the personality and character of the person they knew.

Elderly parents are often reluctant to ask their children for





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help. In my work I frequently meet people who tell me that their children are 'too busy' or 'lead such full lives' that they cannot ask them for any more of their time. This is a great pity and I would urge anyone who feels like that to think again. As you build your team, you will find that the amount of time and effort you ask from each helper is actually relatively small. Whilst it is true that adult children with families of their own may be very busy, most will be glad to help out – perhaps bearing in mind that the opportunity for these acts of kindness will not always be there.

Other family members such as brothers and sisters, cousins, nephews and nieces, if they have always been close and regular visitors, can play a valuable part in the team.

Tell family members about the diagnosis and ask your family to help.

Ask friends

Many people withdraw from society when dementia enters their lives. As explained in the section on Lifestyle (chapter 9), this is a bad thing in itself. However, for many people it becomes a big effort to keep their social life going. They may fear that friends are becoming less involved and withdrawing from their social circle. Many people think that dementia carries a 'stigma', which reduces their social circle and the number of people who might otherwise act as a support network.

The fact is that true friends do not feel this way. Friends care about those whom they have chosen as friends. Even casual acquaintances are often willing to help. The problem seems to be one of understanding. Good friends who want to help need to be kept in the loop so that they can understand what effect dementia has and how they can continue to be good friends and to offer their support as required. Ask your friends to help according to their ability.





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I thought my friends Pam and Roger had become rather stand-offish. Pam always seemed in a hurry and although she seemed glad when I called she often did not invite me in as she had done in the past. If I asked after Roger she usually said that he was busy 'in the garden' or that he was still in bed (which I thought seemed very odd). It was only one day when I found her in tears that it all came out. Roger had Alzheimer's disease and she had been trying to keep it hidden. She seemed to be ashamed of the fact and felt embarrassed at allowing me to see Roger. Actually because it was quite a few months since I had seen him I thought Roger had changed a lot and was very confused and he didn't seem to know me. I stayed talking with him for half an hour that day and by the end of the visit he was actually talking much more sensibly and seemed more like the Roger I knew. I asked Pam if I could come again the next day and now I call round two or three times a week and often go for a walk with Roger or pop into the pub for a quick drink with him. It seems a small thing to do as we have always been friends.

Ask neighbours and casual acquaintances

While we generally hope to get along with our neighbours, most of us would balk at the idea of asking them to do anything more onerous than perhaps taking in a parcel if we are out. But your neighbours will be familiar to the person with dementia – he or she may forget their names but is still likely to know that the neighbour is someone familiar. It may be your neighbour who spots the person with dementia outside looking lost. It is likely to be your neighbour who notices the day the person with dementia misplaces his/her key and cannot get into the house.

Your neighbours often know quite a lot about your life and most people want to be good neighbours. If you explain the





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situation to your neighbours and help them to understand dementia they can be a tower of strength.

My husband wandered out of the front door one day while my back was turned and if it hadn't been for my neighbour spotting him I wouldn't have known in which direction he had gone.

Tell your neighbours about the person with dementia and ask them to help you.

Use professional carers

You may decide early in the illness to employ professional carers, either to help with tasks you find difficult (including giving personal care) or to look after the person with dementia so that you can have time to yourself to carry out essential tasks or to go shopping or visit the hairdressers or meet the bank manager – any one of a hundred occasions when you do not want to be distracted. (Remember that you may be entitled to some help with care costs (see page 181).)

Some people do not want to employ a professional carer until they absolutely have to, either because they do not want to introduce a stranger into the household or because they feel guilty at 'not managing' everything themselves. Others prefer to pay someone to help with certain tasks from the diagnosis onwards. One advantage of doing this is that the person with dementia will have time to get to know them and to trust them. Also, as the main carer, you will also have time to decide whether they fit on your team and whether you can trust them to fulfil whatever duties you wish to give them. Remember that dementia is progressive and that you may need help at a later stage with things that are easy to manage earlier on. Agency care





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can be increased as and when you need it, but doing this is easier if you have built up a relationship with the care agency and its staff.

One other aspect of using professional carers is the fact that in such a case no one is doing you a favour. You pay for the care you want and you can expect the standard of care you pay for. You don't have to feel grateful to the carer, although of course you may do so and if you feel the standard falls short, you can say so and, if necessary, try an alternative agency.

Remember, the carers who staff a day centre are professional carers, specifically trained and selected because they enjoy working with people who have dementia. They will have experience and skill and can become part of your support team. If you are lucky enough to have contact with a local dementia adviser or support worker from an organisation such as the Alzheimer's Society, this person too will be a valuable part of your team. You can turn to them for advice and information at any time that you need to.

CHOOSING AND BUILDING YOUR TEAM

It is important to make a plan so that you know exactly what you do need rather than letting yourself feel overwhelmed. What are the gaps that the person with dementia once filled? What do you find difficult?

Building your support team is one of the most important things you can do in coping with dementia. Who you choose for your team depends upon many factors. You need people who can help you to do the things you cannot do or which you find difficult. You need people who are willing to help the person with dementia do the things that he/she can no longer manage alone. The person you are caring for may have played an important part in the activities of your everyday life. For example, he or





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she may have been good at DIY and kept the home ticking over by changing plugs, putting up shelves or painting and decorating. Or perhaps he/she did the cooking, housework or laundry. Someone will have to take over these duties gradually. That someone may be you or you may decide to find someone who can do these things for you. You also need people to give you some respite – that is, time off from your caring duties

Of course, everyone's needs are different. You will have to think ahead. Some people find personal care for a partner or parent no trouble – they consider it part of a loving relationship. Others find that providing this type of care interferes with their established relationship. Some people enjoy finding simple pastimes or non-challenging activities for the person with dementia to do – others find this extremely tedious. Some carers find outings and social occasions with the person who has dementia enjoyable. Others find them embarrassing or frustrating. There is no need to feel guilty or force yourself to do things that may lead you to be short tempered and less patient with the person you care for.

A calm and patient carer makes for a calm and contented person with dementia. You need to help yourself as well as the one you are caring for.

Generally most people find that, if they cannot cope with personal care, then paying for a professional carer from a reputable agency is the best option. Often, although initially resistant, the person with dementia prefers a professional to help with intimate care.

Friends, relatives and neighbours are the best option if you want to arrange for someone to take part in leisure activities and pastimes with the person with dementia, although some professional carers from an agency will also do this.

Kind neighbours and friends may carry out DIY, maintenance or gardening tasks, but you may prefer to find a local handyman





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or gardening service you can call on when needed. It is hard to keep chasing a busy neighbour up about a task without feeling you might be nagging.

If you need help with housework, cleaning and laundry, you can pay for a cleaning service. Some professional caring agencies also include light housework among their carer's duties.

If you can afford to, you can pay for help with cooking, but it may be easier to learn to do this yourself and there are so many convenience foods available these days that most people can eat quite well even if they are not accomplished cooks. (See the tips on nutrition in chapter 9 and remember that people with dementia need nutrient-rich foods). Alternatively, you might make a meals delivery service part of your team.

For outings, friends and family are probably the best people to call on.

People who, take the person with dementia out, who carry out activities with them or even just sit and keep them company, are all providers of respite care – they enable the main carer to have some time off. Day centres and residential respite care in a care home also allow for longer periods of respite, when the carer knows that he/she will have a whole day, several days, or even a week's break from the constant caring duties. There is further discussion of respite options in chapter 12 (see page 202).

Inviting people to join your team

People may want to help but only feel able to join your team if you ask them to do something specific. Then they will know what you need and whether they can be relied on to do it.

You may think that asking people to be on your team is a daunting task. It may seem to you as if no one would want to take on the tasks you need help with. In fact, most people (once they understand what the diagnosis of dementia means to you) will





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be pleased to help. You don't have to tell them they are joining your team in so many words. You can simply ask them to help.

When you do ask for help be very specific. If you say, 'As you know. John has dementia and it would really be kind if you could lend me a hand with him now and again,' people will probably smile and say, 'Of course – just give me a call.' This means that you have to stiffen your resolve later to ask the favour again. It is best at the outset to say something like, 'It would be lovely if you could come and sit with John on Thursday afternoons,' so that everybody is clear about what is needed.

First think about what sort of help you need. Try to think ahead a bit, because dementia is a progressive condition. Just because John can find his way down to the paper shop each morning and buy a paper and find his way home again now, doesn't mean that he will always be able to do this. Of course, dementia develops differently in each individual so planning is not easy. If you don't feel confident about how the progression might go, you can talk to a dementia support worker about this. The clues are often there. Someone who has lost his/her way once will be liable to do this again, although maybe not every day. Someone who has difficulty signing his/her name will probably lose the ability to write quite soon, although he/she may be able to carry out many other activities of everyday living.

Once you have an idea of where you need help, decide who might be best placed to offer help in that area and then ASK THEM. A specific request is more likely to get a straightforward answer, whether positive or negative.

Here are some examples of straightforward specific requests:

'John is likely to get confused and lose his way these days. Would you be able just to walk down to the paper shop with him in the mornings to keep him company in case he gets confused?'

'Your father would love to go to the pub for a drink occasionally.'





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Could you call round once a week and take him?’

‘Can you take your mother shopping on Saturday to buy some new underwear?’

‘Thank you for offering to help. I know Fred would like to keep up his outings to the football club. Would you be able to call round and go there with him on Mondays?’

‘Mollie would like to keep going to church on Sundays and in the past I’ve been happy to take her and pick her up. But she sometimes gets confused now when she is there on her own. As you go to the same church, could she go with you and sit with you during the service? I’d be happy to take and collect you both in the car.’

With requests like this you are asking for only one specific piece of help and whoever you ask knows what is expected of them. If you are clever and think about the members of your team, you will find you are only asking people to do what they are already doing. You are just making the arrangement more clear cut. If your husband has always gone to the football club with the neighbour two doors down and you ask for this arrangement to continue, your neighbour is unlikely to feel awkward about it. On the other hand, because you have made a specific request he/she will not be tempted to allow the regular outing to drop because ‘Fred isn’t up to it any more’, until that genuinely is the case.

Potential team members may need to know more about dementia. They may be concerned it makes sufferers violent, though this is rarely the case. Recommend they visit the websites listed at the end of this book, or print off spreadsheets from the Alzheimer’s Society for them.





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If some of your 'team' ask for more information about dementia, try to make sure that they can access it. You can give them the information you know yourself but some people prefer to read the facts at their leisure so that they can take them in at their own pace. The factsheets issued by the Alzheimer's Society (www.alzheimers.org.uk) are an excellent source of authoritative information and they can be downloaded from the Society's website or ordered from them by phone. You can also tell your team about any carers' information courses that are being run locally, or lend them suitable books. Your dementia support worker, if you have one, will be pleased to explain about dementia to members of your team. Try not to listen to spurious media information such as, 'It said in the Daily X today that there is a pill to cure dementia' and be prepared to gently discourage any well-meant attempts to 'put you right' as a result of this.

My husband's friend was very kind and helpful at first but then he started telling me that he had read on the web that 'people with Alzheimer's are frightened of water'. I was having difficulty in getting Peter to shower sometimes but this seemed to be more because he couldn't get himself going in the mornings. I got very confused when his friend started saying this but I noticed that once in the shower Peter really enjoyed his wash. I changed our routine so that he showered before bed, which was when he was less sluggish and this worked quite well.

What to do if someone says no

Supposing someone refuses your request for their help? It may be because they are frightened and worried. Many people believe that those with dementia 'become violent' and there is certainly a tendency for the general public to associate the confusion and





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frustration felt by someone with dementia with violence. If this is the case, helping the worried person to understand more about dementia will make a difference – again use the sources of help and information detailed above. Although people with dementia may become agitated and even hit out if put in a really difficult situation, most retain their sense of what is acceptable public behaviour and do not do this. (See also the section on ‘challenging behaviour’ on page 56.) In this situation it may be good to ask someone like a nurse or a dementia adviser or support worker to explain the facts to your potential helper.

Sometimes people may feel unable to help because they are afraid of being put under an obligation or of agreeing to an arrangement they may not be able to keep. It is worth giving your helper a get-out clause, when making your specific request for help. For example:

‘Of course, I know you sometimes don’t go to church if the weather is very bad and naturally I wouldn’t expect you to put yourself out in that case.’

‘I know the time may come when it will be too difficult to take Fred to the club and when you feel that time has come I will quite understand.’

You need to be able to rely on your team members – if people let you down you will know you have to find someone else.

At least if someone refuses to help, you will know where you stand. It is more difficult to manage the people who agree to help and then do not turn up when expected or make spurious excuses to avoid a regular arrangement. For someone with dementia, any variation in routine is likely to arouse anxiety and they will not be able to understand sudden changes in arrangements. No matter how carefully you explain that ‘Jim telephoned to say that





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he couldn't come to the pub with you today because he has to look after the children,' the person you are caring for may react by behaving awkwardly. For you, the carer, an unreliable team member is worse than none at all.

Michael's sister said she would come to spend the afternoon with him while I saw a couple of my friends for coffee and a shopping trip. But she just didn't turn up. Michael had seen me getting ready and we both waited and waited but she didn't even phone to say she couldn't come. We both had a very upsetting day.

In a case like this the best thing is to assume the person concerned will not fit on your team and to try to look for someone to replace them.

The process of building your team and of planning how you might get regular relief from care may seem a major and complicated task and even unnecessary, particularly if you are reading this chapter shortly after an early diagnosis. However, you should take advantage of the fact that you have time to plan and organise: building your team will make your life (and the life of the person with dementia) more tolerable and even enjoyable in the long run.

