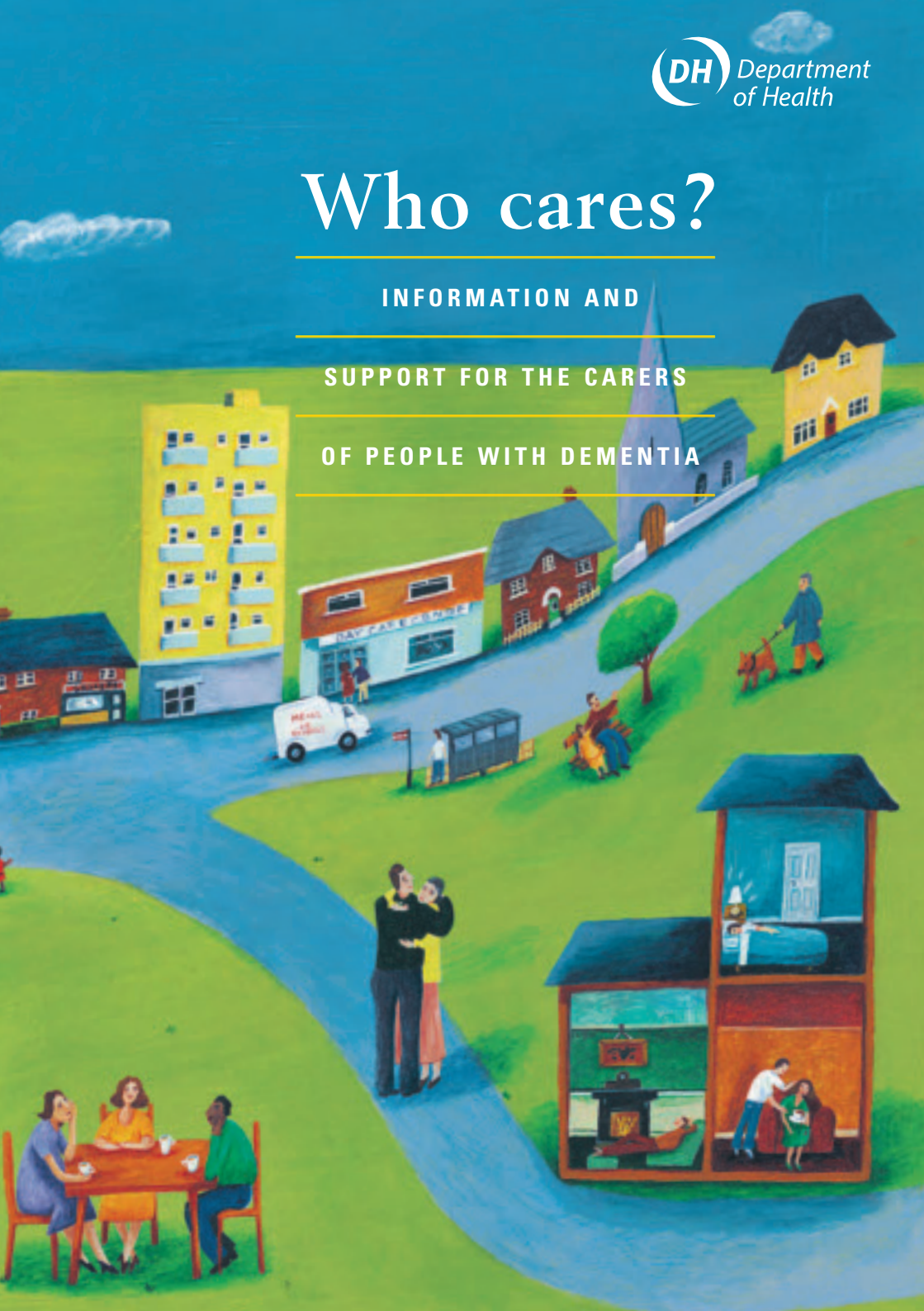


# Who cares?

INFORMATION AND  
SUPPORT FOR THE CARERS  
OF PEOPLE WITH DEMENTIA



# Who cares?

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INFORMATION AND

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SUPPORT FOR THE CARERS

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OF PEOPLE WITH DEMENTIA

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Please note that there may be changes in the benefits system and in social services after publication of this booklet, so you are advised to check benefits and services issues with either your local Citizens Advice Bureau or one of the other agencies listed on pp.91–93.

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*282900/Who cares?* can also be made available on request in Braille, in audio, on disk and in large print.

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# INTRODUCTION

If you are reading this booklet because some of the comments on the back cover struck a chord with you, you may be looking after someone who has dementia.

This booklet has been written to tell you:

- More about dementia.
- What it is like for someone at home.
- How to ease the problems of day-to-day care.
- About the help available to carers.

Dementia is a distressing condition and a lot of what follows in this booklet may be painful to you. But the booklet is not primarily about dementia. It is designed to support you, the carer. It has been written with the advice of many people who are or have been carers themselves and who have shared their experiences to help others. All the examples and quotes used in this booklet are based on what different carers have said. After reading the booklet, you may want to discuss what you have read with someone who is familiar with the condition, such as a doctor or one of the agencies listed on pp.91–93.

It is hoped that these carers' experiences will support you in a task that may at times seem daunting and thankless, and help you realise that you are not alone. Wherever possible the booklet is optimistic – not because anything will be easy, it won't – but because many carers have stressed that whatever the difficulties there are also small triumphs to be won.



## ABOUT DEMENTIA

**D**ementia is a complex and perplexing condition. It includes a number of different diseases, of which Alzheimer's disease is the most common. As a carer you need good information and support to help you understand the condition and its consequences.



## WHAT IS DEMENTIA?

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The term 'dementia' is used to describe the symptoms that occur when the brain is affected by specific conditions, including Alzheimer's disease, stroke and many other rarer conditions. Symptoms of dementia include loss of memory, confusion and problems with speech and understanding.

Different areas of the brain are responsible for different skills and abilities. The changes in behaviours, memory and thought in people with Alzheimer's disease may be a direct result of the way the disease has affected their brain. The causes are not yet understood. There is no cure for dementia, and little treatment can be offered, although new drugs have been developed that may for some people temporarily alleviate some of the symptoms of Alzheimer's disease. Since the same symptoms may result from other disorders, which may be curable, it is important to get a proper diagnosis. Dementia by itself is not usually a cause of death and someone may have the condition for several years before dying from something else.

There are two most common types of dementia. Their symptoms and effects are much the same, although they progress differently:

- In Alzheimer's disease changes take place in the structure of the brain, leading to cell death. The

onset of the disease is gradual and the decline usually slow and regular.

- The second main type of dementia happens when 'mini' strokes take place in the brain, which destroy small areas of cells. This is called 'vascular' dementia. It often progresses in a step-like way and the onset may be sudden. The person may not get any worse for periods of time, and may even seem to improve, although decline will be the eventual outcome. Some people have both Alzheimer's disease and vascular dementia together.

Other types of dementia include Lewy body dementia, Pick's disease, Huntingdon's disease and Creutzfeldt-Jakob Disease (CJD).

## WHO WILL GET DEMENTIA?

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Dementia is usually a disease of older age, with six in 100 people over 65 years of age developing it to some degree, increasing to 20 in 100 among people over 85 years. However, it is estimated that as many as 18,500 people under the age of 65 have dementia. Younger people with dementia have particular and specific needs that are not necessarily dealt with in this book. Please contact the Alzheimer's Society for more information.



## WHAT CAUSES DEMENTIA?

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Because dementia is such a distressing illness and is not fully understood you may have anxieties about the nature of the disease, especially about its causes and your own chances of getting it.

**One carer admitted:**

*"My mother's got it so I can't help wondering about myself. Every morning when I wake up, I think to myself, "Now what did I have last night for my meal? What day is it? Right! I haven't got it – yet!""*

But in most cases dementia is not thought to be inherited.

Many people fear the onset of mental illness in older age, especially as it is often considered to be embarrassing or shameful. Although dementia becomes more common with increasing age, this does not mean that it should be seen as part of normal ageing, nor is it caused by old age.

You may try to explain the disease by finding a 'cause' in an accident or loss that occurred about the same time as the symptoms appeared. Although its onset may appear to coincide with major life changes, such as the death of a spouse or moving house, it will not have been caused by it; nor is it caused by the ageing process.

Nor is there any evidence to support other commonly held beliefs about the causes of dementia. It is NOT infectious and cannot be caught or sexually transmitted, although some people with AIDS do develop dementia. It is NOT caused by 'over-use' or 'under-use' of the brain. However, some research suggests that keeping your brain active can reduce the risk of developing dementia.

At the moment it is easier to say what does not cause dementia rather than what does. However, research into causes and treatments continues. You and the person with dementia may be asked to co-operate in this research. As you might expect, the more people who participate in research, the more likely it is that a cure will be found. With regard to Alzheimer's disease, it is now widely accepted that the cause will turn out to be a multiplicity of factors, which differ in their ability to influence the development of the disease from one individual to another. These influences may involve genetic aspects and environmental factors. The causes of other forms of dementia, such as vascular dementia, CJD and Korsakoff's syndrome, are now more clearly understood.

## WHAT ARE THE SYMPTOMS OF DEMENTIA?

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A major symptom of dementia is that the person consistently forgets things they have just said or done, although their memory for past events may remain perfectly clear. Loss of short-term memory is always a feature of dementia, although it may not become noticeable for some time after the onset of the disease.

There are many other symptoms of dementia, although it is unlikely that one person will develop all of them. Each person with dementia will be affected in a different way. The overall impact of the disease depends partly on what the person was like in the first place – their personality and their physical condition – and on the type of dementia they have. Some people



**The person may be forgetful,  
and confused:**

*We were staying in a hotel we'd been to many times and he didn't seem to know his way about. He couldn't remember where the toilet was.'*

**Behaviour may be slightly odd  
or inappropriate:**

*He kept saying he'd lost his coat and spent ages looking for it, and he had it on all the time!' 'He bought a TV stamp and seemed very proud of himself. But it's something we never do, we never buy TV stamps.'*

**For others the symptoms may  
be more unusual:**

*'It started with hallucinations. He used to talk about a woman in white.'*

with dementia become disagreeable and more difficult to live with. Others become docile and even-tempered. Some will become severely disabled physically while others will be able to manage for themselves with minimal help for a long time.

Although the symptoms do not follow a regular pattern in every case, some changes are more likely to occur at the onset of the disease and others as the disease progresses.

This booklet starts with those changes most common in early dementia – changes that may well be unrecognised at the time and fit into a pattern of declining ability only when the carer looks back. It then describes the symptoms that may develop during the course of dementia. Finally, the booklet gives you an idea of the most severe problems you may have to face, even though this may be worrying and painful if you are at the beginning of caring.

In the early stages of the disease an often-mentioned change is that the person seems different from their usual self in ways that may be hard to pinpoint. Their approach to life is dulled; they seem less capable, less involved and less adaptable in all spheres of life. They may show loss of concentration, seem unable to make decisions or avoid taking responsibility. Carers have described the person as 'not the man he was' or as if 'the life had gone out of her' or as having 'lost her brightness'. More tangible changes may accompany this dullness.

The person with dementia may be just as puzzled by their own behaviour. They may become upset and irritated by their own incompetence, or more wrapped up in themselves. These mood-changes may be noticeable to family and friends too but are not necessarily seen as causes for alarm. Also at this stage of the disease it is still possible to make excuses or allowances for these changes – to put them down to overwork, worry and so on.

As the disease progresses the symptoms become more obvious and disabling. People with dementia may:

- Be very forgetful, especially of recent events and people's names.
- Be muddled about time, day, place and unable to find their way around familiar surroundings.
- Have difficulty in talking, and often repeat themselves.
- Be unable to make sense of what is said to them.
- Have difficulty with carrying out household tasks and neglect personal hygiene.
- Put themselves at risk by leaving pans to boil dry or gas fires unlit.
- Behave inappropriately, like going out in their nightclothes or wandering around the streets at night.
- Hide or lose things and accuse others of stealing them.
- See or hear things that are not there.
- Become angry, upset or aggressive very easily.

**The following examples, recorded by carers, are typical:**

*'After a couple of years she couldn't put a name to things.'*

*'I spoke to him about a plug that wasn't working and all I got was gibberish.'*

*'He stayed in the bedroom one and a half hours to tie his tie ... oh! the frustration! ... He couldn't tie his shoe-laces either, the laces would be at the side, and he'd put his underwear on back to front.'*

*'She could see two men at the end of the bed and swarms of animals crawling over the wardrobe.'*

In the later stages of the disease people may:

- Be unable to remember things they have just said or done.
- Not recognise known faces and familiar objects.
- Be unable to express themselves.
- Be unable to understand what is said to them.
- Be very restless, especially at night.
- Try to carry out actions or re-live events from their past.
- Be unable to carry out household and personal hygiene tasks without a lot of help and supervision.
- Have bladder and bowel incontinence.
- Have to use a wheelchair.
- Be bedridden.

### WHY SHOULD YOU GET A DIAGNOSIS?

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It is very important to get a proper diagnosis of dementia. A diagnosis is essential to:

- Rule out other conditions that may have symptoms similar to dementia and that may be treatable. These include depression, chest and urinary infections, severe constipation, vitamin and thyroid deficiencies and brain tumours.
- Rule out other possible causes of confusion, such as poor sight or hearing, emotional changes and upsets, such as moving or bereavement, or the side effects of certain drugs or a combination of drugs.

- Access advice, information and support from social services, voluntary agencies and support groups.
- Allow the person with dementia to plan and make arrangements for the future.

Identifying the type of dementia is becoming increasingly important as drugs for treating different conditions become available (see section on *Treatment* on p.29).

## DEPRESSION AND DEMENTIA

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There is a complex relationship between depression and dementia. The symptoms of dementia and depression, including withdrawal from social activities and general apathy, may seem very similar. An older person with severe depression occasionally may be misdiagnosed as having dementia.

The situation is further complicated by the fact that the person with dementia may also be depressed. Dealing with the consequences of a diagnosis of dementia, a major life event in itself, may trigger the onset of depression. There may be a sense of loss and a period of coming to terms with the diagnosis.



If you are looking after someone with dementia-like symptoms, ask your doctor to start the process of diagnosis (see *Medical help* on p.27). When, and only when, a diagnosis of dementia has been made, there will be some difficult decisions to be reached (see *Your emotions as a carer* on p.15 and *General guidelines for caring* on p.53). It may be helpful to speak to your General Practitioner (GP) at this point because she or he can help you start to make plans about things like finances and enduring power of attorney for the future.



## YOUR EMOTIONS AS A CARER

People find themselves looking after a confused person at home for many different reasons – out of love, from a sense of duty, perhaps because they feel they have no choice. Some find assuming the responsibility relatively easy. Others come increasingly to resent it. This chapter suggests ways of coping and coming to terms with your emotions.







However you approach your caring responsibilities they will certainly arouse a great many conflicting emotions in you, and in your family. In part, your response will be affected by your relationship with the person with dementia. Those caring for partners will almost certainly experience different feelings from sons or daughters caring for parents, or a sister for a brother. Also, whether the previous relationship between the person with dementia and carer has been close or distant, whether there has been love and companionship or indifference and dislike, will affect the strength and range of your emotions.

So many of these emotions are negative that it is easy to become overwhelmed by them, and to feel that you are alone in trying to cope with them. But you are not alone. All these emotions – and no doubt others besides – have been experienced by carers other than you and are a common part of the caring process. Finding other carers to talk to as soon as you can may help you to come to terms with your feelings and provide much needed support (see *Help for the carer* on p.25).

While you may feel any or all of these emotions at any time, certain feelings may occur at different stages, usually linked to the progress of the disease or to your understanding of it.

## IN THE BEGINNING

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You will have noticed some of the symptoms before you know the person is ill, probably before you have had any professional advice or outside help from any source. You are likely to be puzzled, bewildered, even alarmed. What accounts for the odd and upsetting changes in behaviour and personality? You will probably be trying to find an explanation on the one hand – ‘He’s working too hard’ – and denying that there is a problem on the other – ‘After all, she’s always been a bit absent-minded’. But inside, you may be afraid because you sense an almost indescribable change that you don’t understand. Other people may not have noticed anything amiss. Even your GP may dismiss your fears lightly. For many carers this may be a very difficult time – and the time when least help and support will be available or offered.

*‘Why is he behaving like this?’*

*‘What’s the matter with her?’*

*‘I must be imagining things.’*

## WHEN THE ILLNESS IS DIAGNOSED

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Not that it’s easy once a diagnosis has been made. It may be reassuring to have it confirmed that the person really is ill – and you can begin to prepare for the changes that will have to take place in your lives. But it will take a while for the implications of the disease to sink in. It may be hard, if not impossible, to accept that there is no cure and that the person will not get better. But it is important to remember that many people in the early stages of dementia, even after having a diagnosis, can live a relatively independent life. You will be apprehensive about how you will manage in the future and anxious about what

*‘Why can nothing be done?’*

*‘Is she really not going to get better?’*

*‘Why me? Why us?’*

*‘I hated everybody at first. I had a grudge against everything and everybody.’*

*'I shall never come to terms with it as long as I live.'*

*'At the beginning you think you will never cope, but if you love a person and you're with them all the while, you do. It's hard, it's very, very hard, but you do grow into it, you learn by your mistakes.'*

discomfort or anxiety the person with dementia will experience. This may extend to wishing to protect them from knowing the diagnosis. You may be overwhelmed by the prospect of having to care for someone who may become very ill and angry that fate has singled you out.

There are no glib assurances for any of these misgivings and carers differ in their ability to come to terms with the diagnosis.

Carers do not find their task easy. But many agree that there is a process of becoming a carer which can be learned, and which makes caring less of a burden.

Caring can also bring its own rewards – satisfaction when things go well, an opportunity to express your love for the person you care for, or perhaps to return care that you received as a child.

## **COPING WITH CARING**

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*'Why don't other people understand?'*

*'How will I cope?'*

*'Is this still the man I was married to for 40 years?'*

By this stage, the illness may be causing real difficulties in carrying out normal day-to-day activities, and this will be the time when you may have to make major adjustments to your way of life. Ordinary tasks like dressing and eating a meal may take twice or three times as long as they used to. Some very irritating ways of behaving may have developed and the illness may be straining family relationships. Teenage children may find it particularly difficult to adjust. Such problems are likely to make you feel

tense and anxious until you find ways of getting round some of them.

You may feel hurt by changes in the personality of the person with dementia and their responses to you. An affectionate gesture may not be returned or even recognised.

Nevertheless, you may feel very protective towards them, and caring for them can bring strong feelings of tenderness and compassion.

The illness may also become more obvious to outsiders, and some of the things the person does may cause you severe embarrassment, especially when strangers, or even friends, don't understand or are intolerant of 'odd' behaviour. Because of such difficulties, you should do your best to avoid becoming isolated from your former social life, and from feeling increasingly lonely. (*Personal support for carers* on p.44 suggests ways of avoiding it.) Anyway, you don't always owe people an explanation, but you may be pleasantly surprised about how well they react once they understand the situation.

*'I told some of the old ladies round here. I told them "Now Clifford's getting forgetful he may do odd things, he may come and knock at your door." One old lady said "By Jove, I'd be glad if he did. I've not had a man to see me for ages!"'*

*'That Saturday he followed me all over, even going to the toilet ... it really got me uptight. I told him to get away from me but he didn't. I had to beg him to get away. He went out of the kitchen and I slammed the door after him.'*

## FEELINGS OF AGRESSION AND GUILT

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But, however well you adapt to the new situation, feelings of anger and aggression are certain to surface from time to time. You may feel angry that this has happened to you. You may be frustrated that more is not known about the disease so that effective treatment and a cure can be offered. Doctors and other professionals may seem unconcerned and slow to provide help, as may other members of your family. And at times you will get angry with the person and their irritating behaviour.

Sometimes carers reach a point where they are physically aggressive towards the person they care for. This is a clear signal that the carer needs a break from the situation and more support. This may be obtained from social services, Alzheimer's Society, Age Concern, Carers UK, your local Princess Royal Trust for Carers centre and many other voluntary organisations. There is also the Elder Abuse Response Line, phone: 080 8808 8141, which is available from 10.00 am–4.30 pm Mon–Fri, for those who are concerned about abusing the person they are caring for.

Losing your temper with a person with dementia is something about which carers often feel guilty, although it may be reassuring to know that most carers admit to it. People also feel guilty about many other things – for example, for the way they treated the person in the past, for resenting having to look after them, for wanting them to go into permanent care, or for wishing them to die. Feeling guilty is a common and understandable reaction when confronted with a trying and often inexplicable disease like dementia, though feeling guilty will probably do neither you nor the person you care for much good. One carer confessed that he sometimes had trouble coping but he saw no reason why he should feel guilty about being less than perfect.

*'I've heard the word "guilt" used ... it gets up my nose. I don't feel guilt at all and I think it's an abomination that people should use the word guilt when a carer has been looking after someone as best they can ...'*

You may also feel frightened if you have to take over making decisions in the family, which were previously made by the person concerned. Remember that specialists have told you that the person you care for can no longer manage their own life. If you don't accept the responsibility, things will not run smoothly for either of you. When you have to do it, it is reassuring how much you can accomplish, with the right support and help.

## IN THE LATER STAGES

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*'To think of him, bless his heart, he's always been a good son and a wonderful husband ... to have this degrading business happen to him. One thing I will say – he doesn't know – which is fortunate.'*

The person with dementia's personality may have changed almost beyond recognition, and they may have lost many of their faculties. This is certainly more distressing for the carer, who is keenly aware of what is happening, than it may be for the person themselves.

Sometimes, the person with dementia may have some insight that he or she is not the person they were, not in control of the situation and feel sad and frustrated. Having someone there for them is often reassuring even though sometimes this may mean not saying very much. Non-verbal communication can often mean more than what is said.

At this time you may experience a great sense of sadness and begin to mourn the loss of the person you once knew. You may also find that you can no longer cope with the situation and reach a state of despair. You may wonder what all the hard work and emotionally exhausting care are for and ask yourself: 'What's the point – wouldn't she be better off dead?'

If this happens, you should look at alternatives. Caring at home does not necessarily have to last until the death of the person in your care. If the stress becomes too great, you should consider having the person you care for looked after permanently in care homes.

You can find more information on care homes in this booklet. Turn to page 32 and *Useful organisations* on p.91. This does not mean, of course, that you will cease to care. Carers emphasise the benefits of visiting the person they have cared for in their new home and say that it can restore a relationship that has been soured by the stresses of caring.



The transfer to permanent care in a home may induce a sense of grief, almost as if the person had already died: 'When she first went in, I can only say it was like a bereavement.' But visiting regularly can be important, even if the person doesn't recognise you: 'It's a form of therapy for you – the figure of the person, although the character's gone.'

For some, this period of grieving before death will mean that you have begun the mourning process and started saying your goodbyes. This is a natural reaction to the prolonged stresses of caring without receiving a response from the person concerned. You should not let other people's opinions upset you if they do not understand your reaction. It is quite a usual one.

After the person's death you may at first feel a great relief that so much distress is over. It could be some while before the normal process of bereavement takes place. You may also have to grieve twice over – once for the person with the dementia and once for the person you knew and loved before their illness.



If you have been caring for a long time and have given up your job and much of your social life you may need help to pick up the pieces and start again. Contact Carers UK, which sometimes runs ex-carers' groups at a local level.



## HELP FOR THE CARER

Looking after someone with dementia at home can be distressing, and is almost always hard work. But many carers say that they also get satisfaction from helping the person, and they still have some good times together. Certainly many carers want to keep their relatives at home until caring becomes too heavy a burden. But if you are going to care for someone with dementia at home, it is essential that you should seek help.



## WHY SHOULD YOU SEEK HELP?

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It is important to realise that coping at home can cause you, the carer, severe strain. You may be an older person yourself, not in the best of health, and you may have difficulty with the physical demands of caring. If the person lives alone in their own home, you will have the responsibility of running two households and the worry of wondering what is happening when you're not there. You may even have to spend a lot of your caring time travelling between your home and theirs. Having the person live with you and your family may cause tension because of the demands they make on the household.

Whatever the arrangement, caring for someone with dementia is likely to have effects on your health, family life, leisure, employment and finances. That is why you should always seek help as soon as you suspect that your relative is ill. Don't wait until you are desperate before you ask for help. An extra pair of hands, some time off for you to relax, or a bit of extra income may be enough to see you through a crisis.

Even if you don't think you need help now, find out what is available and how long it takes to arrange – in some cases it may be weeks or even months. Then when you sense you're going to need help, you can try and start the process in good time.

Always be prepared to ask for help. Services are provided because it is known that people like you

need them, and it is your right to ask for them. Also don't forget, your well-being is as important as that of the person with dementia.

There are four main areas of help about which you should know – medical, personal, practical and financial. Key addresses are provided in *Useful organisations* on p.91.



### Medical help

Your General Practitioner (GP) is the first person you should contact when you suspect that your relative is ill so that you can get a proper diagnosis of their illness. Doctors vary greatly in their attitudes towards people with dementia. Some aren't interested, some are inexperienced or not very knowledgeable about the condition, others may wish to protect you from knowing the worst about the disease and so appear to be unconcerned. Others are very helpful, being both sympathetic and also providing practical help.

Carers have suggested that you need to be firm and persistent with GPs who aren't immediately helpful. If you are really getting nowhere it is legally possible to change your GP, although this is not always practically possible. If you wish to change your GP, you can simply go to a new doctor – or visit several and then choose – and then ask to be put on the list. If the new doctor agrees, then the arrangements will be made through the new doctor and the health authority. If you can't find a GP, then your primary care trust (PCT) must



assist. For details of your local PCT, call NHS Direct on 0845 46 47.

You can request that your GP (or the practice nurse) carries out an annual health check for over 75s. If you are worried about the health of a person with dementia who is over 75, this could be a good way of getting their needs assessed. At the check up, which can be done in the person's home, there should be a chance to talk about problems the person with dementia may have. If it seems appropriate, you can ask for the person to be referred for specialist assessment and treatment.

A good GP will act as a key to all the other services provided by the National Health Service. This will include referral to hospital specialists for further assessment if necessary, and for treatment. A GP can also provide access to community nursing staff who can help and advise you at home. Normally, your GP is the only person who can refer you to hospital specialists unless the person with dementia is admitted for emergency treatment. Hospital specialists can also put you in touch with community nursing staff.

It is important that as a carer you do not lose sight of the need to look after your own health and well-being. You should ensure that your GP knows that you are a carer and find out what local services are available to support you. These might be general or specific to carers of people with dementia.

You should also make full use of your local social services office, voluntary organisations and carers and support groups. You can contact all of these directly (see *Useful organisations* on p.91).

### **Treatment**

No drug treatments can provide a cure for Alzheimer's disease. However, drug treatments have been developed that can temporarily slow down the progression of symptoms in some people. Aricept, Exelon and Reminyl all work in a similar way and are known as cholinesterase inhibitors. There is also a newer drug, Ebixa, which works in a different way from the other three – but at the time of publication of this booklet, it was not generally available on the NHS. For more information on the drugs available to treat Alzheimer's disease, the Alzheimer's Society free information sheet 407, which gives an overview of the medications available, may be helpful and is available from [www.alzheimers.org.uk](http://www.alzheimers.org.uk) (see also *Useful organisations* on p.91). Alternatively, talk to someone from your local specialist dementia team. You can ask your GP how you might do this.

Sometimes, medication to calm someone is useful, but it is important to use the correct dose, as some people can be very sensitive to these drugs. Of course it's also very important to treat other illnesses, like bronchitis, quickly and you should see your GP if there is a sudden, even if minor, change.



### **Personal support for the carer**

A major risk for carers is that you may become socially isolated. Looking after someone with dementia takes more and more of your time. Their odd behaviour may annoy or embarrass friends and neighbours who may stop calling round. You may become afraid to leave them alone at home because they have become a danger to themselves. But struggling to manage on your own increases the stress on you, and reduces your ability to cope. Stopping yourself from becoming isolated is an essential part of coping with caring.

There are three main things you can do:

- First, make sure that you get a break from caring – some time to pursue your own interests or hobbies, to visit friends, or simply to get on with everyday tasks without having to worry about supervising the other person. The break may be for just one evening a week, for one or several days a week, or even time for a proper holiday. However long, the idea is to give you a rest or the opportunity to take part in other activities. Getting a break may also help the person with dementia, offering them a chance to socialise with others and take part in different stimulating activities. Many carers find day-care useful and suggest that you start it as soon as possible so that the day-care staff can learn to adapt to any problems as they worsen. Your GP or local social services department should be able to help you arrange a break.

- Second, carers can never stress enough the benefits of talking to other people who understand your problems. Those most able to understand are obviously other carers. It is often easier to talk to people from outside the family. Carers' support groups, where carers meet regularly to share their experiences and to help each other, exist locally in many parts of the country. Where no group already exists, you might want to set one up yourself. Your GP may be able to advise you about local specialist services or alternatively the Alzheimer's Society or Princess Royal Trust for Carers (see *Useful organisations* on p.91) will be able to help and advise you on local contacts and services.
- Third, where at all possible, you should try to share the responsibility for caring with other members of your family, or with friends and neighbours. Women, in particular, often find that they are expected to care for a sick relative, though many carers are, in fact, men. Both women and men carers should encourage others to help them. Family members may not realise how hard a time you're having unless you tell them. Until you ask for help they may assume you don't need it. Sharing housework and organising care rotas would spread the load more fairly. Friends and neighbours may be able to help in many ways, particularly if you explain the illness, and its effects on the person with dementia and on you.



### Practical help

Health and social services and some voluntary organisations such as Crossroads and the Dementia Relief Trust (see *Useful organisations* on p.91) may be able to offer help with a number of practical tasks in the home, like providing regular nursing care and domiciliary services. They may also supply safety aids for the bathroom or stairs, equipment such as commodes and a laundry service. If you can afford it, it is worth spending money on anything that will relieve you of daily tasks, such as a washing machine.

If you are sure that you have made full use of all possible help available at home but you are starting to find it increasingly difficult to cope, you should find out whether it will be possible to have the person with dementia cared for permanently in a care home. The availability of such care varies throughout the country, and the ways of paying for it are complex. It is very important that you seek good advice about what kind of care may be possible: contact one of the *Useful organisations* on pp.91–93.

The following is just a brief description of how care might be arranged.

If you feel you will need help with paying for residential care you should contact your local social services office. They will also advise more generally on the availability of care homes in your area. Useful organisations include the Elderly Accommodation Counsel, which maintains a

nationwide database on all forms of accommodation for older people. Counsel and Care and The Relatives (& Residents) Association also provide information.

Help the Aged provides a free Care Fees Advice Service (phone: 0500 767476). They also publish a leaflet, *Care Homes*, available by post, from Help the Aged charity shops or from [www.helptheaged.org.uk](http://www.helptheaged.org.uk). Age Concern also publishes a series of factsheets. Factsheet 29: *Finding care home accommodation* and factsheet 10: *Local authority charging procedures for care homes* are available from the Age Concern website at [www.ageconcern.org.uk](http://www.ageconcern.org.uk) or free by post from Age Concern. For details of all these organisations, see *Useful organisations* on pp.91–93.

Your choice of private care also depends on what you can afford, although there is state help in many cases. You should obtain a proper diagnosis of the person's illness before they go into private care. You may have to be very persistent to obtain permanent care, so don't give up hope if you fail at the first, second or even third attempt.

### Financial help

Finally, caring may substantially alter your financial circumstances. If you are working, you may have to go part-time or give up your job altogether; fuel bills may rise because more time at home means more heating; laundry costs and money spent on clothing may increase if the person with dementia becomes incontinent.



Both you and the person you care for may be entitled to extra cash in the form of welfare or disability benefits. To find out what you may be entitled to, contact your local Jobcentre Plus or social security office. You will find their phone number and address in the phone book under social security. You can also get leaflet SD1 *Sick or disabled?* from your local Jobcentre Plus, social security office, the post office or from [www.dwp.gov.uk/publications/dwp/2003/sd1\\_oct.pdf](http://www.dwp.gov.uk/publications/dwp/2003/sd1_oct.pdf).

You can also ring the Benefit Enquiry Line for people with disabilities (phone: 0800 88 22 00) – a freephone number that can give confidential advice to people with disabilities and their carers. It is open Monday to Friday, 8.30 am–6.30 pm, Saturday 9.00 am–1.00 pm. Advisers can go through a claim form with you over the phone and fill it in for you. If you want, they will send you information in a letter after your call. They can also provide leaflets giving more details. Information on more specific benefits is given on pp. 48–52. The Department for Work and Pensions, leaflet SD4 *Caring for someone?* is aimed specifically at carers. It is available from your social security office, post office or from [www.dwp.gov.uk/publications/dwp/2003/sd4\\_oct.pdf](http://www.dwp.gov.uk/publications/dwp/2003/sd4_oct.pdf).

### **Don't give up**

The medical, practical and carer support services will vary according to where you live. Some areas are well provided with services, others less so. You should find out now what is available near you, and keep a record of how and where to make contact. There is space to

do this on the back cover of this booklet. Go to your local social services office and ask for an assessment for the services that are available – both for yourself and the person you care for. Look under your local authority in the telephone directory. Alternatively, your GP may be able to help. The library and Citizens Advice Bureau will also be able to help, and the *Useful organisations* section pp. 91–93 will give you some ideas too. Remember it is your right to ask for the medical and social services that are available in your area, and you need to take up what is on offer before a difficult task becomes impossible and leads to your own ill health.

Many carers become extremely discouraged if several attempts to get help have failed. But it is worth persevering. Most carers eventually find their way into the network and are relieved and even delighted by the help that is provided.

As always, the first step is the hardest. The support you get will be worth your extra effort.

*'We'd been trying to persuade our doctor to do something for months. Finally he contacted a specialist. We didn't know anything about it – until the specialist just called on mother at home. And he's been wonderful ever since, putting us in touch with so much other help.'*

## A WHO'S WHO OF HELP

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### Your local health authority

- Your GP can refer you to the following hospital and community services.

### Hospital services

- A **psychiatrist** – medical doctor specialising in mental illness for any age group.
- A **neurologist** – specialist in diseases of the brain and nervous system.
- A **geriatrician** – specialist in diseases of older people.
- A **clinical psychologist** – specialist in mental and behavioural functions of the brain.
- An **old age psychiatrist** (used to be called **psycho-geriatrician**) – specialist in mental illness among older people.

### Community services

- A **district nurse** provides nursing care at home.
- A **health visitor** provides general health advice at home (you can ask to see one for yourself at your local health centre or clinic).
- A **community psychiatric nurse** provides nursing care for mentally ill people at home. Sometimes there are aids for practical care.
- A **continence adviser** offers advice about the management of incontinence.
- A **chiropodist** provides foot care.
- An **annual health check** offered by the general practice to look at the needs of people over 75.

### Social services

- A **social worker** – assesses and plans the support needed by people at home. They will either arrange the support package or organise a direct or indirect payment.
- A **care manager** – usually a social worker but may be someone like a district nurse, an occupational therapist or someone from a home care organisation performing the same role.
- An **occupational therapist** – provides rehabilitation at home using daily activities.

One of the first things you need to do is to get an assessment of need carried out by your local social services office. Section 2 of the 1970 Chronically Sick and Disabled Person's Act lists the services that social services have to consider during an assessment. These include day-care and home help. Once social services have decided that someone needs any of the services listed in this Act, they have a duty to ensure that the need is met. Should the service not be available locally, then it is the ultimate responsibility of social services to ensure that the need is met by bringing in services from outside of their area. You might find Age Concern's factsheet 41: *Local authority assessment for community care services*, helpful. This is available from [www.ace.org.uk](http://www.ace.org.uk) or free by post (see *Useful organisations* on p.91).

### **Direct payments**

Alternatively, from April 2003 every local authority will have to offer money to those who are eligible, instead of arranging services for them. When a local authority gives someone money in this way, it is known as a direct payment. Your social worker should discuss this option with you when they assess your care needs.

The Department of Health has published: *A guide to receiving direct payments from your local council*, (to obtain a copy phone the DH Publications Orderline: 08701 555 455, quoting reference 31006). The National Centre for Independent Living can provide further information and advice about direct payments, and refer you onto a local support service (see *Useful organisations* on p.91).

### **Assessment**

Talk to your local social services office or hospital social worker about the assessment procedures in your area. The Carers and Disabled Children Act (2000) strengthens the rights of carers to an assessment of their own needs as carers. It gives local authorities a responsibility to support carers either by providing services to the person with dementia or to the carer directly, helping them to take a break or through a direct payment for services provided directly to them. Local authorities may also have a short-break voucher scheme set up to help support carers with breaks that are flexible and accommodate their needs.

The person (or people) carrying out an assessment will look at the needs of the person with dementia and the carer and, in co-operation with them, try to work out the most suitable package of services. There will be an assessment of ability to pay for many of these services, and the assessor will want to ensure that all available state benefits are being claimed.



Different people may be involved in the assessment. An occupational therapist may advise on dealing with practical problems, and perhaps arrange for equipment to be provided in the home. As a result of the needs assessment, a variety of help may be arranged – meals, home care, respite breaks, day care – depending on what is available locally. If the kind of help that you need is not available, you may need to work hard to have it arranged. This is sometimes easier to do in co-operation with others in the same situation.

### ***Care plan***

After the assessment is complete and any relevant discussions have taken place, the person assessing should devise a care plan with you. Make sure that you get a copy of what is agreed.

### ***Reviews***

As the situation changes, the care plan will need to be reviewed. You should be told whether social services will review these needs on a regular basis and, if so, how often and when, or whether it is up to you to get



in touch with social services. If there has been a change in either your own or the person with dementia's situation and you need more help or different kinds of services, get in touch with social services at once, whether or not there is a regular review.

### *Carers*

The Carers and Disabled Children's Act 2000 came into force on 1 April 2001. This provides carers with new rights and enables local authorities to help carers to care. The Act states that:

- Carers aged 16 or above have a right to an assessment of their needs.
- Local authorities should provide services for carers.
- Local authorities may charge for these services.
- Instead of receiving the service, carers can ask for a direct payment allowing them to organise services themselves.
- Local authorities can give vouchers for short breaks.

The legislation allows local authorities to provide services for the carer in addition to extra services for the person they are caring for. The carer's assessment considers whether the carer has any needs in relation to the care they provide and whether the local authority should be meeting those needs.

New legislation for carers places additional duties on councils when they are assessing carers. Since 1 April 2005, councils must inform carers of their right to an assessment of their own needs. Councils must also take into account whether the carer works or wishes to work or undertake education, training or leisure activities.



A new deal for carers' was announced in early 2007 which proposed improved support for carers through a range of measures. These include:

- Updating and extending the Prime Minister's 1999 Strategy for Carers and encouraging councils and PCTs to nominate leads for carers' services;
- Establishing a national helpline to offer advice to carers;
- Ensuring that councils can offer short-term, home based cover for carers in crisis or emergency situations;
- Creating an Expert Carers Programme which will provide training for carers and help them to develop the skills they need.

### ***Complaints***

Each local authority has a complaints procedure, which you can use if you are not happy with any aspect of the services provided. You can use this procedure if you are told that the person you care for will not receive an assessment and you think they are entitled to one, or if the services you need are not provided or are unsatisfactory.

The local authority will explain how to use the complaints procedure. However, try to sort things out on a personal level, as there may have been a failure in communication or a misunderstanding. If you use the local authority complaints procedure and are dissatisfied with the results there are other avenues of complaint. However, these are usually very complex so ask advice first.

## VOLUNTARY ORGANISATIONS

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These are charities and other non-statutory bodies that provide many services to supplement those provided by health and social services. There are too many to list here, and they vary from area to area, but some examples are:

### Local information and financial advice

Your nearest Citizens Advice Bureau

### Carers' support groups

Age Concern\*

The Alzheimer's Society (specialises in dementia\*)

Carers UK\*

Dementia Relief Trust\*

Mind\*

The Princess Royal Trust for Carers\*

### Getting a break

Age Concern\*

British Red Cross Society

Crossroads\*

Women's Royal Voluntary Service (WRVS)

For information on schemes local to your area, contact your town hall or Citizens Advice Bureau.

\*Contact details given in *Useful organisations* pp.91–93.

## PROBLEMS AND WHO CAN HELP

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### Medical help for someone with dementia

#### 1. Finding out what's wrong

diagnosis of the illness

your GP will make the initial diagnosis and may refer you to a hospital specialist for an assessment

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#### 2. Regular health care

to keep a check on the progress of the illness and any other minor complaints that might be treatable.

GP, practice nurse, district nurse

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#### 3. Nursing care at home

help with bathing, getting out of bed

domestic home care agencies

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dressing sores, etc.

health visitor, district nurse

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general health advice, e.g. about diet, constipation, keeping safe and avoiding falls, etc.

health visitor, dietitian, GP

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help with emotional and behavioural problems

community psychiatric nurse

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assessment for equipment such as a commode or walking frame

occupational therapist (social services or health)

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difficulty in walking caused by lack of foot care

chiroprapist

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Your GP or specialist should put you in touch with most of these people. You can contact the health visitor directly at your local health centre or clinic and you can contact the occupational therapy department through social services

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## PROBLEMS AND WHO CAN HELP

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### Personal support for carers

#### 1. Carers' assessments

a chance to talk to someone about what would help you social services

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#### 2. Getting a break

sitters, minders, care attendants come into your home for a few hours a day to give you the chance to get out social services, voluntary organisations

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**day care** where the person with dementia is taken to a local day centre for an agreed number of days a week allowing you to go to work or have some time for yourself social services, local health authority, voluntary organisations

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**short-term residential care (sometimes called respite care)** where the person with dementia goes to a home or hospital for a period of between a weekend and a month, possibly on a regular basis social services, local health authority, voluntary organisations

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**permanent residential care** where the person with dementia goes into a home social services, local health authority, voluntary organisations, private nursing or rest homes

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#### 3. Carers' emotional problems

someone to talk to social workers, practice nurses, doctors, health visitors and other health workers may be sympathetic listeners, there may also be specific counselling services available.

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## PROBLEMS AND WHO CAN HELP

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### Personal support for carers *continued*

#### 3. Carers' emotional problems *continued*

Some voluntary organisations provide trained counsellors. There is a growing network of carers' groups set up by voluntary organisations and some health authorities and social services departments. Carers UK and the Alzheimer's Society provide excellent support in this area

Some people may find religion a comfort

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## PROBLEMS AND WHO CAN HELP

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### Practical help

#### 1. Help in the home

home care to assist with personal care, practical help around the house and shopping social services

community meals or meals-on-wheels will provide one hot meal for an agreed number of days a week, usually only for the housebound social services, voluntary organisations, WRVS

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#### 2. Safety

a brief demonstration of the correct method of lifting or moving the person with dementia could avoid injury to both of you district nurse or physiotherapist

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bath aids – grab handles for the side of the bath, bath seat, bath mat, non-slip mat for inside bath, shower fitment hand rails for stairs and more major adaptations to your home such as installing a hoist or a downstairs toilet occupational therapist for larger items; other items from bathroom shops, department stores, etc.

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adaptations for cookers and fires local electricity and gas boards, social services

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## PROBLEMS AND WHO CAN HELP

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### Practical help *continued*

#### 3. Incontinence

treatment/management	GP, continence adviser
incontinence pads	district nurse, continence adviser, local Primary Care Trust, chemist shop
commodes	voluntary organisations, local health authority
special clothing for protection or to make dressing and undressing easier	district nurse who can also tell you where you can buy them
laundry services, where available, may provide and wash bed linen	social services, local health authority

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## PROBLEMS AND WHO CAN HELP

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### Financial help

You should get independent advice from your local Citizens Advice Bureau on what and how to claim *before* you go to the relevant office. Help the Aged produces free advice leaflets including *Can You Claim It?*, which provides excellent advice in this area. Carers UK's website, Carers Online, also provides some useful background information on benefits. Go to [www.carersuk.org](http://www.carersuk.org) or see *Useful organisations* on p.91

Citizens Advice Bureau

**Income Support** is a cash benefit to help people who do not have enough money to live on and who are not working 16 hours a week or more. It can be paid to top up other benefits, or earnings from part-time work, or if you have no money at all. Pension Credit is available to people who are aged 60 or over. Contact your local Jobcentre Plus, social security office or Pension Service office for further information

Department for Work and Pensions

**Disability Living Allowance (DLA)** is a tax-free benefit paid out regardless of income for people under 65 who have an illness or disability and need help with personal care and getting around. DLA has two components:

Department for Work and Pensions

- A care component (payable at one of three rates)
- A mobility component (payable at one of two rates)

For more information see the leaflet *Disability Living Allowance*, available from social security offices and post offices.

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## PROBLEMS AND WHO CAN HELP

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**Attendance Allowance** is a cash benefit for people disabled at or after the age of 65 who need a lot of looking after because of their physical or mental disablement. There are two rates – a lower one for people who need a lot of looking after by day or night, and a higher one for people who need a lot of looking after day and night. It is paid regardless of income and savings and can be paid on top of other benefits, including Income Support. See the leaflet *Attendance Allowance*, available from social security offices and post offices

Department for Work and Pensions

If you need help in completing the forms it may be a good idea to make an appointment with your local Citizens Advice Bureau (CAB). Many CABs are happy to help people with this task

Citizens Advice Bureau

**A Disabled Persons Tax Credit (DPTC)** is available to people who are able to do some work but have a disability that puts them at a disadvantage in getting a job. It is a tax-free, income-related benefit for people who are working for at least 16 hours a week or more. For more details get claim pack *Disabled Persons Tax Credit*, DPTC/BK1, from the Inland Revenue, your local social security office or post office

Inland Revenue

**Carer's Allowance** is a taxable benefit paid to people aged 16 or over who are caring for a severely disabled person for at least 35 hours a week. The carer must be earning no more than £82 a week after the deduction of allowable expenses and the person in their care must be getting the middle or highest rate of Disability Living Allowance care component or Attendance Allowance or Constant Attendance Allowance. For more information get claim pack DS 700 *Carer's Allowance*, from your local social security office

Department for Work and Pensions

You may not get the Carer's allowance if you are already getting another benefit paid at the same or higher amount, such as State Pension. However, you may be able to get a carer premium or extra money for caring added to some social security benefits. Do speak to your local Jobcentre Plus, social security or Pension Service office about this. In some cases the person cared for may lose some of their benefit if Carer's Allowance is paid. Seek advice if this is the case

## PROBLEMS AND WHO CAN HELP

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**Home Responsibilities Protection** is a way of ensuring that people don't get less state pension because they take time off work to look after someone who is sick or disabled. It is available for complete tax years for which a person is caring – for at least 35 hours a week – for a sick or disabled person who is getting the middle or highest rate of Disability Living Allowance or Attendance Allowance or Constant Attendance Allowance for 48 weeks or more. For more information get CF 411 *Application Form for Home Responsibilities Protection*, from your social security office or post office. Someone who is getting Carer's Allowance will not need to claim Home Responsibilities Protection as they will be credited with National Insurance contributions

Department for Work and Pensions

Further information about social security benefits and entitlements can be found on the Department for Work and Pensions website: <http://www.dwp.gov.uk/lifeevent/benefits/>

If you do not have access to the web, please contact the DWP Public Enquiry Office, phone: 020 7712 2171 (Mon–Fri 9.00 am–5 pm). Or write to: Department for Work and Pensions, Correspondence Unit, Room 112, The Adelphi, 1–11 John Adam Street, London WC2N 6HT.

It is sometimes possible to draw up a **Deed of Covenant**. This is a tax-free means of paying money from one person to another.

You should seek advice on drawing up a Deed of Covenant from a solicitor or accountant

**Council Tax.** If the degree of disability is severe, people with Alzheimer's disease may be exempt from the tax. There is also Council Tax Benefit for those on low incomes. For more information, get the latest *Council Tax Information Sheet* from Help the Aged (see *Useful organisations* on p.91).

Your local council office

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## PROBLEMS AND WHO CAN HELP

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**Housing Benefit.** If you are a tenant you may be able to get help with your rent Your local council office

**Assistance with residential care-home fees.** If the person you care for enters residential accommodation and requires help with care-home fees then you need to contact your local council's Social Services Department. The Social Services Department will carry out a care needs assessment first and then determine if they qualify for financial assistance. If they do qualify then they will work out what you will have to pay on the basis of a national set of charges for residential accommodation rules. Generally, the Social Services Department will agree the fees and will ask the resident to make a contribution

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The local social services have the discretion to disregard the value of the resident's home where appropriate, for example, if you are someone who is a companion of the resident and have given up your own home in order to care for someone who now needs to enter residential accommodation. The value of a resident's home is not automatically taken into account for the financial assessment if it is occupied by the resident's partner or a relative who is over 60, an incapacitated person or someone aged under 16.

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It is also recognised by local social services that, if a person needs temporary care, the local council has the discretion to charge a fee level that ensures that the partner staying at home, who may be a carer, is left with sufficient income to live on by adjusting the resident's personal expenses allowance.

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## GENERAL GUIDELINES FOR CARING

A key to caring for someone with dementia is understanding what it feels like to have dementia and acknowledging that they may be depressed and anxious at times if they realise what's happening to them.





Problems may include:

- Loss of memory, a declining power to think and general confusion. This affects their ability to know what they are doing, why they are doing it and how to do it. As a result, tasks may be carried out incorrectly or dangerously, may be left unfinished or not attempted at all.
- Difficulty holding a conversation and expressing themselves. This leads to an inability to explain their difficulties and to ask for appropriate help.
- Loss of physical co-ordination. This leads to difficulty and possible risk or danger in carrying out actions.
- Embarrassment and frustration about declining abilities, and resentment of having to be helped. This may lead to attempts to conceal their difficulties, resistance to offers of help and a refusal to carry out certain tasks at all.

### **KEEP THINGS NORMAL**

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A diagnosis of dementia does not necessarily mean someone no longer has mental capacity or that you must suddenly start treating the person like an invalid. In fact, you should try and make a point of keeping things as normal as possible for as long as possible. Carry on any pursuits that you have both found enjoyable, such as going to the pub, theatre or cinema, listening to music, singing or dancing, unless, or until, it stops being a pleasure.

Introduce new activities if they seem appropriate – people with dementia often enjoy the company of small babies or children, and animals.

## RETAIN INDEPENDENCE

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There are two major reasons for retaining the person's ability to carry on independently for as long as possible. First, it helps them to retain some sense of dignity and self-respect, and may avoid frustration being brought on by feeling helpless. Second, it makes less work for you – the more they can do for themselves, the less you have to do for them.

Encourage them to carry on with things they can manage. When something becomes too difficult, don't give up on it completely – it could be broken down into smaller or easier bits. But be sure to recognise when something really is beyond them. Don't show them up or put them in a position where they fail. Praise them when they complete a task successfully or for any help they can give you.

Cut down on what they do on their own slowly, and reluctantly, for as one carer said: 'Once you stop something, you've only to stop it once and that's it.'

All the same, it is no kindness to the person to expect them to continue making decisions that are beyond their capabilities. Brace yourself and start to decide what has to be done when the doctors confirm that the person with dementia can no longer manage for him- or herself.



## AVOID CONFRONTATION

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There will be many occasions when you and the person with dementia will have disagreements. You might think it's time they changed their dirty clothes, but they don't agree. They believe someone's stolen money from their purse, you know they haven't. They insist it's perfectly all right to go out shopping dressed in their pyjamas, you'd rather not be with them when they did!

In fact, arguing usually won't get you very far. It generally leads only to frustration and aggressive feelings for both of you. It's far better to avoid confrontation whenever you can. Try not to contradict them if they say strange or silly things. Distract their attention if they want to do something inappropriate by changing the subject, or moving them away from the source of the trouble – the chances are that in a moment or two they'll have forgotten what it is they wanted to do anyway.

Experienced carers have lots of suggestions about how to persuade a reluctant person to do what the carer wants. Avoiding confrontation can be a spur to your imagination.

## AVOID CRISES

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There will be occasions when the person suddenly seems to get more confused, to behave particularly badly or to cry for no apparent reason and be unable to explain why. These may be caused by crises in their

lives – events that seem normal enough to those unaffected by the disease, but alarming to someone who is already confused.

A crisis might be having to hurry to get somewhere on time; meeting too many people at once, even if they are people familiar to them; or going into new and unfamiliar surroundings.

Some of these crises can be avoided. Always try to leave plenty of time to prepare for an outing, or to get a task done. Make sure that only one or two friends or relations visit at once. Accompany the person to new places. If you take them away on holiday, try to go somewhere where both your problems and theirs will be understood. Above all, try and stay calm yourself.

There will be times, though, when crises cannot be avoided, for example, when you are to have a break and a sitter comes in, or the person you care for is to go to a new day centre. On these occasions simply try to reduce the disorientation they are likely to feel by using a family friend or neighbour as a sitter, or by introducing a stranger in slow stages and with you present. The introduction to a day centre or hospital should also be made gradually.

Don't avoid making any changes at all or stop your social life just to avoid crises for the person with dementia. Sometimes they are inevitable and may be best for them – or for you – in the long run.

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## ESTABLISH ROUTINES

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Routines are vital in caring for someone with dementia. Doing the same thing at the same time every day helps them to remember, and so helps you in your task. And if life is predictable and familiar, there is less chance of increasing confusion.

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## MAINTAIN A SENSE OF HUMOUR

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*'The greatest thing I found ... I could get my wife to laugh at everything she did wrong. Everything she did silly, like trying to get her knickers on over her head, I'd say "What are you putting them over there for?" And she'd say: "I'm sure I'm going daft" and we used to laugh.'*

There may be times when you can see the lighter side of things, and it is important for your own mental health that you maintain the ability to laugh. The person with dementia may still be able to enjoy a good joke or a funny situation too, and it will do you both good to laugh together.

Of course, laughing WITH someone is quite different from laughing AT them, which no one should ever do.

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## MAKE THINGS SIMPLER

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A person who is already confused will find making straightforward decisions, or carrying out relatively simple tasks, over-complicated and difficult. Taking a bath, for example, involves many separate actions, from putting in the plug to turning on the taps and obtaining the right temperature, getting undressed, and so on.

Try to simplify things: don't offer too many choices (two is probably enough), break tasks down into short,

simple sections; if a task becomes too difficult ask them to do only part of it.

Make things simple for yourself too. Don't fight lots of battles at once but try and solve problems one at a time. That way you stand a better chance of success.

## MAKING THINGS SAFER

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The dementia patient's difficulties increase the risk of accidents in the home and you should take great care to make your home as safe as possible.

Loss of physical co-ordination increases the likelihood of falls, so you should check your home for danger zones, such as a loose banister rail, slippery floor mats, awkwardly placed furniture, or carpets that may not have been fixed down securely. You may need to have an extra stair rail fitted, along with handrails in the bath and toilet.

Loss of memory and thinking ability can give rise to risks from a number of everyday activities. A person with dementia may turn on the gas fire but forget to light it; they may drop lighted matches into a waste-paper basket; they may scald themselves on a boiling kettle. Some of the solutions are obvious – switch off the gas at the mains when you go out, don't leave matches around, hide kettle flexes. The list is a long one, and largely a matter of common sense. You should review your home for all potential accidents and take action to avoid them.



*Useful information on avoiding slips, trips and broken hips is available from Help the Aged, at [www.helptheaged.org.uk/Health/HealthyAgeing/Falls/default.htm](http://www.helptheaged.org.uk/Health/HealthyAgeing/Falls/default.htm). Or call the Department for Business, Enterprise and Regulatory Reform Publications Orderline for an information leaflet on 0845 0150010.*

## MAINTAIN GENERAL FITNESS AND HEALTH

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The general state of health of the person with dementia will affect their overall condition. If good general health is maintained it will help to preserve existing physical and mental abilities for as long as possible as well as encouraging independence and sustaining morale.

### **Keeping a check on the condition of someone with dementia**

As the main carer you are the best person to monitor any changes in the condition of the person you care for. They will still catch the common colds, coughs and minor complaints that make everyone uncomfortable. However, they are also more prone to certain ailments, such as chest infections, and are more likely to fall. People who are unable to move easily and who spend much time in one position may develop pressure sores or hypothermia in cold weather (a serious drop in body temperature, which can lead to death). All these things need to be carefully looked for, as the person may not be able to explain to you what is wrong and may experience needless discomfort. Sometimes you may be able to give a remedy yourself, but do remember that even everyday drugs such as aspirin may worsen their symptoms unless given in small doses. A check with your doctor is advisable if the symptoms persist, or if you are unsure what to do.

A district nurse, social worker, or GP who makes regular home visits can also look out for any changes and reassess the person's needs. They can refer the person with dementia to specialists or services for particular problems, such as incontinence. A GP can prescribe medicines that may give relief from problems such as sleeplessness and walking at night, depression and delusions, although care needs to be taken when prescribing drugs as they can increase the confusion.

### **Diet**

As the disease progresses there may be problems with the practical side of eating, and tastes for food may alter. If someone is experiencing difficulty with eating or swallowing their food this may lead to problems with getting a balanced diet. Your GP can refer you to a speech therapist who can give advice on these sorts of problems.

It is most important to try to include all the ingredients of a balanced diet, especially as the symptoms of dementia can be worsened by an inadequate diet. Try to provide something they like to eat from each of these food groups every day:

- Meat, fish, eggs, pulses (dried peas, beans, etc.).
- Fruit and vegetables.
- Cereals and bread.
- Dairy produce, milk, cheese, etc.

Make sure they drink enough liquid to prevent them becoming dehydrated or constipated. If constipation

becomes a problem an increase in high fibre foods, such as wholemeal bread, cereals and fruit and vegetables, will help. For more dietary advice ask your GP or health visitor.

### **Physical activity**

Physical activity can be pleasurable as well as helping to preserve existing abilities. The kind of exercise depends on the person's condition and what they are used to, but the best kind of activity is usually something they like doing such as walking, dancing, gardening, swimming or playing bowls – at least until these things become impractical. As the disease progresses, a gently stroll in familiar streets or a park may be more suitable.

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### **KEEP CHANNELS OF COMMUNICATION OPEN**

*‘He can’t get the words ... He knows what he wants to say and he expects me to know. He gets angry and very frustrated. The only consolation is that five minutes later he’s forgotten and gone on to something else. His frustration doesn’t last – it lasts more with us.’*

As the person's dementia progresses there will be increasing problems of communication between them and others. There will be difficulties for them in expressing themselves and for carers in explaining things and making themselves understood. This will affect daily activities and the expression of thoughts and feelings.

Talking becomes a problem for the person with dementia. They may use the wrong words, forget words completely, endlessly repeat words or phrases and lose the thread of the conversation. This can be distressing for both them and the carer.

There are several things that can be done to help maintain open channels of communication. At a practical level it is extremely important to check that the person's senses are not additionally impaired by, for example, a hearing aid that does not work properly, dentures that are too loose, or glasses that are no longer the correct prescription.

In conversation you should remember to speak clearly, simply and slowly and to talk about only one topic at a time. Allow extra time for the person to reply. You may need to repeat things several times, find a simpler way of saying something, or guess the sense of what they are saying. If the person is confused, remind them of basic information gently, perhaps by using a picture or object. Try not to contradict or embarrass the person by correcting them bluntly.

Of course, speech is not the only or the most important way of communicating. Body language – the way we look at a person, how close we move towards them, how we touch them – can be more important than words alone. In the later stages of dementia, looking and touching may be the main ways of expressing affection and care for the person, and their body language also gives you clues about what they mean and how they are feeling.

**This woman's mother no longer recognises her, but they still communicate:**

*'I spend an hour sitting with her with my arm round her cuddling her and I tell her that she's the loveliest mother I've ever had, and she just keeps rubbing my hand and face and saying "I like you".'*

## USE MEMORY AIDS

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In the early stages of dementia memory aids may be useful. These are things that may help to jog the





memory, clear confusion and disorientation, and keep things as normal as possible.

Here are some things carers have found useful:

- Frequently remind the person with dementia of the time, day and where they are.
- Keep a clock with a large clear dial on view.
- Keep a calendar that can be changed by the day, month and year.
- Label the doors of rooms, such as the bedroom and lavatory, with words, pictures and colours.
- Keep photos of familiar people and the family on view.
- Leave the personal possessions of the person with dementia where they can easily find them.
- Keep furniture in the same place.
- Keep checklists of things to do that day, or lists of expected visitors, which can be ticked off.
- Set things out in the order in which they have to be done.
- Leave out only the things required, for example, one day's drug supply.
- Leave a simple, clear note with an address if you are going out.
- Don't forget textures, tastes and smells can also evoke memories.

*'Their world stands still. He doesn't know what 3.30 or Tuesday mean, so what's the point in telling him?'*

*'Supposing he remembers? There he is sitting in a wheelchair, can't walk half a yard, and there am I trying to bring his memory back.'*

Eventually, however, as the disease progresses, even these aids may become less useful as these comments from carers show.



## DEALING WITH COMMON PROBLEMS

**P**eople with dementia may not be able to carry out everyday tasks on their own.

For example, they may lose their ability to cook or wash themselves, and may not recognise the need to go to the toilet. This chapter highlights common problems and suggests practical solutions on how to deal with them.

## DRESSING

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People with dementia sometimes don't remember which clothes should be put on, in which order, nor how to put them on. They may end up wearing several skirts and no underwear, or with things on back-to-front or done up incorrectly. They can have difficulty doing up buckles, laces, bras and so on. They may not recognise the need to change their clothes, for example, when they are dirty or if they are going to bed. They may choose to wear inappropriate clothing – for example, going out in the daytime in their nightwear.

### Possible solutions

Try laying out clothes in the order they have to be put on. Avoid clothes with complicated openings and fastenings. Replace buttons with zips and Velcro (but show them how to use them), buckles and belts with elastic, lace-up shoes with slip-ons and men's 'Y'-front pants with boxer shorts. Choose women's bras with a front opening.

You may need more persuasive tactics to overcome the last two problems. They may resent interference. Don't argue, try to encourage instead. Set out the clean clothes saying, 'These are the clothes you chose to put on', or 'That dress really suits you'. You may have to become tolerant of their preferences. One carer's father frequently wore four pairs of trousers at one time, another's mother went to the day centre in her dressing gown. But ask yourself if these sort of things really matter – for whom is 'problem' behaviour a problem?

## WASHING AND BATHING

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Forgetting to wash and no longer recognising the need may be problems for people with dementia. They may have forgotten what to do, or be unable to wash certain parts of their body because of physical impairment. Some will be unable to climb in or out of the bath safely or manipulate taps. They may be embarrassed by helpers seeing parts of their body usually kept private, and may refuse to wash at all. These problems are increased if they are incontinent and need to wash frequently.

### Possible solutions

Try to establish and maintain a routine for washing. You will need much tact. You cannot tell them to wash but perhaps you can emphasise the more pleasant aspects, the comfort of warm water, perfumed soaps and so on. You may have to tell them step by step what to do, wash with them, or clean your own teeth to demonstrate. You may have to help or supervise them because of physical difficulty and risk of accident or injury. There will be difficulties for the carer too if the person they care for is large or heavy and needs to be lifted. You may be able to get a bath attendant or aids, such as rails and a bath seat, which may alleviate some problems (see *Practical help* on p.46).

Incontinence can be a real problem, especially if embarrassment leads to concealment. It can also be a problem for the carer who may be just as uncomfortable. Try to be matter-of-fact: 'You know and

I know that you're wet, and you'll get sore if you don't wash'. Telling them off or showing that you are upset won't help.

## GOING TO THE TOILET

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People with dementia may forget to go, leading to incontinence and constipation. They may forget where the toilet is, even in their own home. There may be problems undoing their clothing in time. At night they may lose their way in the dark or mistake some other object, such as a waste-bin, for the lavatory.

### Possible solutions

At regular intervals either remind them or take them. Label the door, or paint it brightly. Make sure clothing can be easily removed. (Try some of the possible solutions from *Dressing* on p.66.) Take them before they go to bed. Leave a lamp with a low wattage bulb on, use night-light plugs or stick luminous tape on the wall as a guide. A pot by the side of the bed may help – this used to be common practice for most people when lavatories were outdoors.

The RADAR National Key Scheme offers independent access to disabled people to locked public toilets around the country. The key is free of charge (though in some cases VAT will be charged) and can be obtained from RADAR on [www.radar.org.uk](http://www.radar.org.uk) (see *Useful organisations* on p.91).

## COOKING

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The problems are most severe if the person with dementia lives alone. The ability to cook even simple meals may be lost. Just buying food and keeping it fresh may be beyond their capacity. They may eat food that has gone bad or, in some cases, even pet food. The gas cooker may be switched on and left unlit, pots may be left to burn. Poor physical co-ordination can lead to burns and scalds or cuts from utensils. The combination of these problems leads to malnutrition in many people with dementia who live alone.



For those living with others, the problems are diminished if the carer cooks for them – the problem then may be for the carer who is unused to buying or cooking food.

### Possible solutions

There are a few safety devices that can be fitted to cookers to prevent some of these problems (see *Practical help* on p.46). Invest in an electric kettle that switches itself off. Remove sharp knives and other potentially dangerous utensils. You may need to visit daily to help or supervise – or arrange for someone else to be there. Try to get the meals-on-wheels service to call (see *Practical help* on p.46), but check to see that the person knows how to open the container. You may need to put the food out on a plate for them if they don't understand what the carton is for.

Most libraries stock books about cooking on a range of themes – 'for beginners', 'for small households', 'for those on a budget' and so on.

## EATING

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Many people with dementia forget whether or not they have eaten. Some don't want to eat and claim they have just done so; others want to start on the next meal as soon as they have finished the previous one. They may develop strong dislikes of certain foods and cravings for others. Some don't know how to eat. They may forget how to use cutlery and generally be very messy. They may play with their food, not realising it is to go in their mouth. They may be confused by different foods on one plate. Others have physical problems; they can't chew properly and have difficulty swallowing, which could lead to choking. Some forget to drink and may become dehydrated.

### Possible solutions

Have regular times for eating, and eat with the person with dementia. If they often want to start another meal soon after the last one, keep some washing up in the sink to show the remains of the last meal. If they will eat only certain foods you may have to ask your GP about diet and vitamin supplements.

Don't worry about table manners – spoons are easier than knives and forks, and fingers came first of all! Use plastic tablecloths and place mats so mess can be cleaned up easily.

You may have to remind them how to eat by talking them through each stage, or show them by eating something yourself. Sometimes spoon-feeding may be

necessary. Try to keep food simple. Cut it up or keep it to one texture – soft, thick foods are best. A mixture of liquid and solid may lead them to swallow instead of chewing and could result in choking. Check that dentures fit and are left clean. If the person is experiencing problems with eating or swallowing you can ask your GP for a referral to a speech therapist.

You may find it helpful to provide ‘finger foods’, which are intended to be eaten without cutlery and can help people with dementia to be independent in eating.

Make sure that the person has several drinks a day (at least eight cups/1500 ml), and more in hot weather. It is important to make sure the drinks are not too hot – they may have lost their judgement and hurt themselves. You may need to use a spill-proof cup like the ones sold for children.

## GOING OUT ALONE AND SHOPPING

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The most worrying problem for many carers is the safety of the person they care for (see also *Wandering* on p.74). Traffic presents a threat on even the quietest roads and crowded, busy streets or shopping centres can confuse and alarm. A person with dementia may not recognise even familiar places, and become lost and frightened. Other people are not always helpful and may interpret confused behaviour as drunkenness.

If a person with dementia is shopping alone there are additional problems of remembering what they went out to buy and of handling money.



### Possible solutions

Many carers are rightly reluctant to prevent the person with dementia going out alone as it is often the last thing they can do on their own. Encourage the person to walk in the park or other area safe from traffic and crowds. If this is not possible you may have to accompany them – perhaps take them part of the way to a point where they cannot go wrong, or meet them on the return journey. One carer relied on a well-trained and trusted dog to help her husband cross the road and bring him home.

Persuade them to carry identification – a bracelet or card explaining that they might become confused and showing where you can be contacted. Or sew a nametape into a pocket.

If they are shopping give them a clear note and only the amount of money they will need. They will be able to buy only one or two straightforward items. If they need clothes you will have to go with them. Do not be embarrassed to explain the problem to shop assistants who are usually most helpful once they understand.

### DRIVING

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People with dementia are able to continue driving in the early stages of the disease. However, the DVLA should be told that the person has a diagnosis of dementia so that regular checks on their ability to drive can be made. It is important to remember that it is a criminal offence not to inform the DVLA of a medical condition, such as dementia, which may affect a licence holder's ability to drive.

### Possible solutions

Once you feel that someone should stop driving, broach the subject with them gently. Some may be pleased to be rid of the responsibility driving brings. Others, who resent their loss of independence, may find giving up driving particularly hard. If gentle persuasion doesn't dissuade them from driving, you will have to take firmer action. In the first instance, offer to do the driving (if you can), or suggest using public transport. If need be, hide the car keys or immobilise the car (go to a garage for advice about the easiest way to do this). You can also talk with your GP if you are worried about the fitness to drive of the person you care for. Remember, many insurance companies require a medical certificate of fitness before insuring older drivers.

## ALCOHOL AND CIGARETTES

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If the person is in the habit of drinking alcohol in moderation, there is no reason why it should be stopped. Having a drink may be one of their remaining pleasures, and something you can enjoy together. You should take care, however, that alcohol is not left out where they can help themselves. If they are on medication, remember to check with the GP or pharmacist that the drugs mix safely with alcohol.

The use of cigarettes represents a greater danger. People with dementia may not be safe with matches, and they may smoke in bed, leave lighted cigarettes on the edge of armchairs, or throw them away in waste-paper baskets.

### Possible solutions

Give them a cigarette lighter that cuts off when their finger is removed from the ignition button. If they really need to smoke, it should be only under strict supervision. It is far better to dissuade them from smoking. If persuasion fails, choose a moment when they are otherwise occupied to remove their cigarettes. It may be reassuring to know that many people with dementia forget to smoke so don't miss the habit once it is broken.

## WANDERING

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'Wandering' is a common and difficult problem to deal with. People with dementia may appear to others to be walking aimlessly or anxiously around the home, or wander around the neighbourhood having slipped secretly out of the house. In fact most people with dementia are walking about with a purpose but find it difficult to express what it is. They may walk long distances to old haunts and get lost. You will be worried about their safety and their own bewilderment or fear.

### Possible solutions

If you can work out a reason for the 'wandering' you may find a solution. Sometimes it results from general restlessness and boredom and is a sign that the person needs more stimulation or physical activity. They may be searching for things they think are lost. Keeping personal possessions on view may help here (see also *Losing things and accusations of theft* on p.78). Often they feel insecure and may need both the emotional reassurance that you care and the concrete reassurance

of things being kept in the same places and routines maintained. 'Wandering' frequently starts after a visit to a strange place – for example, after a holiday – or after a change of habit – such as starting at a day centre, in which case it may help if you go with them a few times until the change becomes familiar. Moving home can be very distressing for people with dementia and should be avoided if at all possible.

If you can find no apparent reason for the 'wandering', then you have to prevent them finding their way to places where they will be at risk. You may have to lock some rooms at home and will need to install unfamiliar or difficult locks on street doors. Put the locks on the bottom of the door where they are less likely to find them.

An identity bracelet worn by the person with dementia, giving details of how you can be contacted, is an additional safety measure. If they do still manage to leave the house or walk away from you while you are out, contact the local police who are often able to provide help.

## **NIGHT DISTURBANCE**

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Many people with dementia are restless at night and disturb the whole household by wandering and making a noise. This can be one of the most wearing problems for carers.

### Possible solutions

Again, if you can find a reason, you might be able to alleviate the problem. Some of the more obvious reasons may be that the person:

- Is looking for the toilet.
- Sleeps too much in the daytime.
- Goes to bed too early.
- Needs less sleep.
- Is not comfortable.
- Wakes up and is confused or frightened.
- Thinks it is daytime.

Make sure they have been to the toilet before going to bed (see also *Going to the toilet* on p.68 and *Incontinence* on p.78). Try to discourage long sleeps during the day, perhaps by increasing physical activity. Try to make them as comfortable as possible. A bedside lamp with a low-wattage bulb left on may help if the person wakes up frightened. Sometimes talking gently to the person will reassure them too and send them back to sleep. If they think it's daytime or they think they need to get up for some reason you might have to play along with them as arguing could lead to upset. One carer spoke of her husband who regularly woke at night wanting to go to the shops. She always said, 'All right then, let's go,' walked him round the room and back to bed by which time he'd forgotten where he was going.

If nothing seems to work and the disruption to your own sleep makes you unable to cope, you will have to ask your GP about medication.

## REPETITIVE QUESTIONING AND ACTIONS

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This can be extremely irritating for carers! Usually the person with dementia is unaware of what they're doing, although their behaviour may reflect underlying anxiety or insecurity.

### Possible solutions

There is no point getting angry or saying, 'I've just told you 10 times'. Try to distract them by talking about something else or giving them a different activity. Sometimes writing down the answer helps. Reassuring them of your concern may reduce insecurity. You may also have to develop your skills at turning a deaf ear.

Sometimes it will help to give the person the things they ask for rather than explaining/arguing that perhaps you may have made them a cup of tea five minutes ago. The time spent explaining/arguing can cause more distress or frustration for both parties.

## CLINGING

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Some people with dementia become reluctant to let their carer out of their sight and follow them from room to room. This can be very distressing for you, as it means you're allowed no privacy, often even to go to the lavatory.

They probably behave like this because they're feeling insecure, and the caregiver represents security. When they see you leave the room, they forget that you will come back, and get frightened.





### **Possible solutions**

While you're gone, give them some simple task to do or use the clock to point out when you'll return. Reassure them that you'll be back when the task is finished or when the clock reads a certain time.

If this happens to you, it is important that you use sitters or find some other way of getting a break.

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## **LOSING THINGS AND ACCUSATIONS OF THEFT**

Many people with dementia really do forget where they have put things; others deliberately hide things and then forget. In either case they may accuse you or someone else of stealing the missing items.

### **Possible solutions**

Try not to take their accusations too seriously. Don't deny the charge and get into an argument – it won't be possible to reason with them and they will become more upset. Try to find out if they have a regular hiding place, such as under the mattress or in an old shoe. Keep replacements of essential items, such as keys or glasses. Put away or lock up valuables, money or dangerous things. Get into the habit of checking rubbish bins before emptying them. Make sure that other people who help care for the person are aware of the problem.

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## **INCONTINENCE**

Many people with dementia may be incontinent occasionally and wet the bed. Regular bladder incontinence and bowel incontinence is less usual. But

even the occasional accident can be difficult to deal with. It is embarrassing and degrading for them and distasteful for the carer who has to clean up.

However, incontinence is a condition that can be greatly improved by medical treatment, so ask your GP or health visitor for help.

If incontinence becomes frequent or develops suddenly always check with your GP, as there could be a medical reason.

There could be several reasons for occasional incontinence:

- They forget to go to the toilet.
- They can't get to the toilet in time.
- They can't undo their clothing easily.
- They can't find their way at night.
- They have an attack of diarrhoea.

### **Possible solutions**

- Take the person to the toilet regularly.
- If the toilet is upstairs or some distance from where they spend most of their time try to get a commode (see *Practical help* on p.46).
- Clothing can be adapted by using Velcro instead of buttons or zips. Men's 'Y'-front pants can be replaced by boxer shorts. Your district nurse can tell you about the special clothing that is available. If you're not already in touch with your district nurse ask your GP to put you in touch.



- Provide a pot for night-time use. Use luminous tapes to mark the route to the toilet. Always take them before they go to bed and, if it prevents a wet bed, take them during the night.
- Keep a check on their diet. If they are not eating enough roughage they may develop constipation, which can lead to a blocked bowel and leaking diarrhoea. Increase vegetables, fruits and wholegrain cereals.
- Try to reduce embarrassment by adopting a matter-of-fact approach, directing their attention to the task of cleaning and washing and avoiding any recriminations.
- To protect your furniture use washable covers over dustbin liners. Beds can be protected by using a plastic sheet between a draw sheet (a sheet folded in half and tucked in across the bed).
- Special pads and pants are available from chemist shops or through health authorities (ask your district nurse). Some local authorities provide a laundry service (see *Practical help* on p.46).
- Ask to see a continence adviser who could help with further advice on suitable pads/pants and individual solutions.

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## DELUSIONS AND HALLUCINATIONS

Delusions are ideas that are imaginary, but seem very real to the person experiencing them. Someone experiencing delusions may believe that there are some people who want to kill or harm them, or that objects that are simply mislaid or hidden have been stolen, even by members of the family.

Someone experiencing hallucinations sees or hears things that aren't actually there. They may wake to see figures at the foot of the bed, or hear dead relatives talking to them.

### Possible solutions

Both delusions and hallucinations are imaginary, but they can give rise to genuine feelings of anxiety or panic, and should be taken seriously. It is important to realise that not everyone finds hallucinations unpleasant or distressing, but it's wise to be prepared in case they do.



When the person with dementia is experiencing a delusion or hallucination, don't argue with them or tell them they are mistaken. Remember they are outside the person's control so becoming angry or impatient with them will not help. If the delusion concerns a missing object, for example, try to find it, rather than deny it has been stolen. If the person is distressed by a hallucination explain that you understand what they are feeling, but also that other people cannot see or hear what frightens them. Try to comfort them, perhaps by putting an arm round them or holding their hand, and try to distract their attention on to something real around them.

If the person you are caring for begins to suffer from distressing delusions or hallucinations, you should see your GP. It could be that medication is causing the problem, or the problem itself might respond to drugs.

## SEXUAL RELATIONSHIPS

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The sexual relationship in any relationship is very private and personal and not something that many carers can talk about easily. While dementia does not necessarily affect sexual relationships, the person's attitude to lovemaking may alter. They may not respond to affectionate gestures that you make or they may lose interest altogether. They may simply forget about it.

You may find that you lose interest yourself because of the stresses and tiredness brought on by caring for your loved-one. You may find it difficult to make love with a person whose personality has changed so much.

Occasionally, a person with dementia may become more demanding.

### Possible solutions

There is no simple solution to a complex and sensitive issue such as this. If you find that your sexual relationship is becoming a problem, you should try and talk to an understanding person about it. There are counsellors trained to talk to people about such problems. Your GP should be able to put you in touch with someone.

## INAPPROPRIATE SEXUAL BEHAVIOUR

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In some cases a person with dementia may exhibit inappropriate sexual behaviour, such as undressing in public, exposing themselves, or aimlessly fondling their genitals. In fact, such behaviour is unlikely to be sexual at all. Appearing naked in the sitting room may simply be the

result of forgetting they should get dressed, or of losing their way to the bathroom. A man found 'exposing' himself, may only be trying to urinate in an unsuitable place. One carer's mother seen 'exposing' herself in the street had wandered out in the cold in her nightdress and pulled it up around her shoulders to try and keep warm.

### **Possible solutions**

Behaviours such as these can cause severe embarrassment to carers, but your understanding of the problem – and explaining it to others – should lessen your embarrassment. If the person touches their genitals in public, don't make a scene, but try to discourage them gently. If they appear naked, or start undressing themselves, remove them calmly to another room. It may be worth checking that clothing is not uncomfortably tight, or fastenings broken. In those rare cases where people complain and police or other officials become involved a truthful explanation usually receives a sympathetic response. Whatever happens, do not worry that this kind of sexual action will lead to harmful sexual behaviour – it won't.

## **VIOLENCE AND AGGRESSION**

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The person with dementia's frustration or over-reaction to a difficult situation may occasionally erupt into aggression and violence. When it is directed at the carer it is especially distressing.

The person may also show anger or aggression towards other family members. Several carers



mentioned a particular problem with teenage children, whom people with dementia often seem to resent, perhaps because they represent youthfulness and hope that they know is over for them.

### **Possible solutions**

Whatever you do, do not respond to aggression with aggression. It will only make matters worse. Instead, stay calm yourself – count to 100 if need be – and try to distract their attention. Find out what brings on the reaction – frustration at a difficult task, a certain person's presence, rushing to be ready on time – and try to avoid it in future.

If episodes of violence and aggression become frequent, you should talk to your GP about medication that may help.

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## **FAILURE TO RECOGNISE PEOPLE**

A person with dementia often lives in the past. If a man thinks of himself as still in his forties, it is not surprising that he denies he is married to someone in her sixties or seventies or that he thinks his 40-year-old daughter is his wife.

### **Possible solutions**

Keeping out large photographs of family occasions through the years, so that the person with dementia sees that he (or she) has also grown older has helped some families. Understanding what is happening can relieve the distress carers feel at rejection.



## LEGAL MATTERS

**A**s the dementia progresses, the person with dementia may no longer be able to handle their own financial and other affairs. But help is available from a range of professionals and services. This chapter explains some legal matters and refers you to sources of information.





On a day-to-day level, this may not cause any problems. It is relatively easy for you to take over routine tasks such as paying bills, collecting the person's pension, paying the rent and so on. You can get a form from the Jobcentre Plus, which allows you to collect their pension or benefits. It is important to obtain advice about Enduring Power of Attorney and the Court of Protection at the earliest possible stage (see p.87). Understanding bank managers and others who require the person with dementia's signature on documents may allow you to sign on their behalf. It would be a good idea to get a joint bank account if you have not already got one.

However, it is not wise to allow the situation to drift along. If the person's affairs are complicated (for example, if they own a business or property) you should get expert legal advice as soon as possible about any possible problems before they arise. For example, spouses who own their home jointly may find that they are unable to sell it or, if they do, that they are not entitled to all the proceeds of the sale.

English law provides two ways for a person's affairs to be taken over. The first is Enduring Power of Attorney. The second is the Court of Protection.

### **Enduring Power of Attorney**

This gives one person the legal right to manage another's financial affairs. It can be given only when the person creating the Enduring Power of Attorney is deemed mentally capable. The Enduring Power of Attorney Act 1985 makes it possible to appoint an attorney who has the power to act after the person becomes mentally incapable. The person still has to be mentally capable when creating this power, so it may become common practice for people to appoint an attorney when making their will. It is important, if possible, to establish the wishes of the person with dementia while they are still able to express them. This will ensure you know what they would want when they are no longer able to tell you.

### **The Court of Protection**

This court can appoint a receiver (a member of the family, a solicitor or the Public Guardianship Office) to administer a person's financial affairs if that person has become mentally incapable. The appointment of a receiver takes approximately eight weeks from when the application form is lodged with the court to the receipt of the order by the parties concerned. However, in a case where the assets involved are under the threshold the court can authorise a Short Order if it does not think that the appointment of a receiver is necessary. A Short Order authorises an individual to deal with a person's estate.



If there are financial matters that need urgent attention, parties may apply to the Court for an interim or emergency order enabling financial matters to be managed pending the appointment of a receiver.

### **Mental Capacity Act 2005**

The Mental Capacity Act 2005 allows a person to appoint a Lasting Power of Attorney (LPA) to act on their behalf if they should lose capacity in the future. This is like the current Enduring Power of Attorney (EPA), but the Act also allows people to let an attorney make health and welfare decisions.

The Act also provides for a system of court appointed deputies to replace the current system of receivership in the Court of Protection. Deputies will be able to take decisions on welfare, health care and financial matters as authorised by the Court. They will only be appointed if the Court cannot make a one-off decision to resolve the issues.

The Act also creates a new Court of Protection which will have jurisdiction relating to the whole Act and will be the final arbiter for capacity matters. It will have its own procedures and nominated judges. A new Office of the Public Guardian will be responsible for registering the authority for LPAs and deputies. It will supervise deputies appointed by the Court and provide information to help the Court make decisions.

The Mental Capacity Act 2005 will be implemented in April 2007. Information on current and future legislation on decision making, including Enduring Power of Attorney and applications for appointing a receiver, are available through the Public Guardianship Office. Their address is Archway Tower, 2 Junction Road, London N19 5SZ and they can be reached by phoning 0845 330 2900 or visiting their website at [www.guardianship.gov.uk](http://www.guardianship.gov.uk), until 30 September 2007. After this date the website address will be [www.publicguardian.gov.uk](http://www.publicguardian.gov.uk). There is a specific helpline on telephone number 0845 330 2963. You should go to your Citizen's Advice Bureau, Neighbourhood Law Centre or family solicitor for advice on these matters.



# USEFUL ORGANISATIONS

Some of these organisations publish their own material on dementia and caring for people at home. Some run groups for carers. These are national organisations and many can provide details of local groups.

## AGE CONCERN ENGLAND

Astral House  
1268 London Road  
London SW16 4ER

**Information Line:**  
**0800 00 99 66**

[www.ageconcern.org.uk](http://www.ageconcern.org.uk)

## AGE CONCERN SCOTLAND

Causewayside House  
160 Causewayside  
Edinburgh EH9 1PR

**Phone: 0845 125 9732**

[www.ageconcernscotland.org.uk](http://www.ageconcernscotland.org.uk)

## AGE CONCERN NORTHERN IRELAND

3 Lower Crescent  
Belfast BT7 1NR

**Phone: 028 9032 5055**

## AGE CONCERN CYMRU

Units 13–14  
Neptune Court  
Vanguard Way  
Cardiff CF24 5PJ

**Phone: 029 2043 1566**

[www.accymru.org.uk](http://www.accymru.org.uk)

## ALZHEIMER'S SOCIETY

Gordon House  
10 Greencoat Place  
London SW1P 1PH

**Phone: 020 7306 0606**

**Helpline: 0845 300 0336**

Email:  
[enquiries@alzheimers.org.uk](mailto:enquiries@alzheimers.org.uk)  
[www.alzheimers.org.uk](http://www.alzheimers.org.uk)

## ALZHEIMER'S SCOTLAND

22 Drumsheugh Gardens  
Edinburgh EH3 7RN

**Phone: 0131 243 1453**

**Dementia Helpline:**  
**0808 808 3000**

Email:  
[alzheimers@alzscot.org](mailto:alzheimers@alzscot.org)  
[www.alzscot.org](http://www.alzscot.org)

## BENEFIT ENQUIRY LINE

(for people with disabilities and their carers)

**Freephone: 0800 88 22 00**

Monday to Friday  
8.30 am–6.30 pm; Saturday  
9.00 am–1.00 pm

## BRITISH ASSOCIATION OF OCCUPATIONAL THERAPY

106–114 Borough High  
Street  
Southwark  
London SE1 1LB

**Phone: 020 7357 6480**

[www.cot.co.uk](http://www.cot.co.uk)

## CARERS UK

20/25 Glasshouse Yard  
London EC1A 4JT

**Phone: 020 7490 8818**

[www.carersuk.org.uk](http://www.carersuk.org.uk)

## CITIZENS ADVICE BUREAU

See *under* National Association of Citizens Advice Bureaux

## COUNSEL AND CARE

Twyman House  
16 Bonny Street  
London NW1 9PG

**Phone: 020 7241 8555**

**Advice on residential care and benefits:  
45 300 7585**

[www.counselandcare.org.uk](http://www.counselandcare.org.uk)

## CROSSROADS ASSOCIATION

10 Regent Place  
Rugby  
Warwickshire CV21 2PN

**Phone: 0845 450 0350**

[www.crossroads.org.uk](http://www.crossroads.org.uk)

## DEMENTIA RELIEF TRUST

6 Camden High Street  
London NW1 0SH

**Phone: 020 7874 7210**

## DISABLED LIVING FOUNDATION

380–384 Harrow Road  
London W9 2HU

**Phone: 020 7289 6111**

**Helpline: 0845 130 9177**

[www.dlf.org.uk](http://www.dlf.org.uk)

## ELDERLY ACCOMMODATION COUNSEL

3rd Floor  
89 Albert Embankment  
London SE1 7PT

**Helpline: 020 7820 1343**

[www.patient.co.uk](http://www.patient.co.uk)

## HEALTH EDUCATION BOARD FOR SCOTLAND

Woodburn House  
Canaan Lane  
Edinburgh EH10 4SG

**Phone: 0131 536 5500**

[www.healthscotland.com](http://www.healthscotland.com)

## HEALTH PROMOTION DIVISION, NATIONAL ASSEMBLY FOR WALES

Ffynnon-las  
Tŷ Glas Avenue  
Llanishen  
Cardiff CF14 5EZ

**Phone: 029 2075 2222**

[www.patient.co.uk](http://www.patient.co.uk)

## HELP THE AGED ENGLAND

207–221 Pentonville Road  
London N1 9UZ

**Phone: 020 7278 1114**

**SeniorLine: 0808 800 6565**

**Care Fees Advice**

**Service: 0500 767476**

[www.helptheaged.org.uk](http://www.helptheaged.org.uk)

## HELP THE AGED SCOTLAND

11 Granton Square  
Edinburgh EH5 1HX

**Phone: 0131 551 6331**

**SeniorLine: 0808 800 6565**

[www.helptheaged.org.uk](http://www.helptheaged.org.uk)

## HELP THE AGED WALES

12 Cathedral Road  
Cardiff CF11 9LJ

**Phone: 029 2034 6550**

**Seniorline: 0808 800 6565**

[www.helptheaged.org.uk](http://www.helptheaged.org.uk)

## HELP THE AGED NORTHERN IRELAND

Ascot House  
Shaftesbury Square  
Belfast BT2 7DB

**Phone: 028 9023 0666**

**Seniorline: 0808 800 6565**

[www.helptheaged.org.uk](http://www.helptheaged.org.uk)

## **MIND (NATIONAL ASSOCIATION FOR MENTAL HEALTH)**

Granta House  
15–19 Broadway  
London E15 4BQ

**Phone: 020 8519 2122**

**Infoline: 08457 660 163**

**Publications:**

**020 8221 9666**

[www.mind.org.uk](http://www.mind.org.uk)

## **NATIONAL ASSOCIATION OF CITIZENS ADVICE BUREAUX**

Myddleton House  
115–123 Pentonville Road  
London N1 9LZ

**Phone: 020 7833 2181**

[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

## **NATIONAL CENTRE FOR INDEPENDENT LIVING**

4th Floor  
Hampton House  
Albert Embankment  
London SE1 7TJ

**Phone: 020 7587 1663**

**Fax: 020 7582 2469**

**Text: 020 7587 1177**

Email: [ncil@ncil.org.uk](mailto:ncil@ncil.org.uk)

[www.ncil.org.uk](http://www.ncil.org.uk)

## **NHS DIRECT**

**Phone: 0845 46 47**

[www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)

## **THE PRINCESS ROYAL TRUST FOR CARERS**

142 Minories  
London EC3N 1LB

**Phone: 020 7480 7788**

Email: [info@carers.org](mailto:info@carers.org)

[www.carers.org](http://www.carers.org)

## **PUBLIC GUARDIANSHIP OFFICE**

Archway Tower  
2 Junction Road  
London N19 5SZ

**Phone: 0845 330 2900**

**Helpline: 0845 330 2963.**

[www.guardianship.gov.uk](http://www.guardianship.gov.uk)

[www.publicguardian.gov.uk](http://www.publicguardian.gov.uk)

(from 1 October 2007)

## **RADAR**

12 City Forum  
250 City Road  
London EC1V 8AF

**Phone: 020 7250 3222**

**Minicom: 020 7250 4119**

(Mon–Fri 9.00 am–5.00 pm)

Email: [radar@radar.org.uk](mailto:radar@radar.org.uk)

[www.radar.org.uk](http://www.radar.org.uk)

## **THE RELATIVES AND RESIDENTS ASSOCIATION (FOR ENGLAND & WALES)**

24 The Ivories  
Northampton Street  
London N1 2HY

**Phone: 020 7359 8148**

Email: [relres@totalise.co.uk](mailto:relres@totalise.co.uk)

[www.relres.org](http://www.relres.org)

# LOCAL INFORMATION

## NAMES, TELEPHONE NUMBERS AND ADDRESSES FOR EASY REFERENCE

YOUR DOCTOR

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PRACTICE NURSE

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DISTRICT NURSE

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HEALTH VISITOR

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HOSPITAL SERVICES

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LOCAL AUTHORITY SOCIAL WORKER

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MEALS-ON-WHEELS

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HOME HELPS

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VOLUNTARY ORGANISATIONS

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LOCAL CARERS' GROUP

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CHIROPODIST

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OCCUPATIONAL THERAPIST

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# Who cares?

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*'Who cares? gives information in a realistic, yet sensitive manner.'*

**Alzheimer's Society**



*'We found the book very understanding of the pressures placed on the carer.'*

**Age Concern (England)**



*'The book is excellent and full of practical ways to help carers.'*

**Help the Aged**



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[www.dh.gov.uk/publications](http://www.dh.gov.uk/publications)

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