



## Becoming a carer

A booklet about looking after  
someone with DEMENTIA

# DEMENTIA

## FOREWORD

When my wife was diagnosed with Alzheimer's I was groping in the dark – I didn't know anything about it. And I didn't know where to turn. But then I was put in touch with some of my local carers' organisations, and their advice, support and care made it possible for us to carry on.

If you're going to care for someone with dementia, it's important that you find out as much about their condition as you can. This booklet will give you lots of information, and there are many organisations there to help and support you – some of these are listed at the back.

Secondly, you must be firm. Stand up and be counted - you may become your partner's representative, spokesperson and protector. You will experience many obstacles along the way from many different sources, and you will need lots of patience. Know your rights and enforce them. Carers' organisations can help both you and your loved one to continue as normal a life as possible.

Thirdly, it's important to treat your loved one with dignity and respect. They have dementia, but most things are possible with a little planning. Continue to socialise, go shopping or for a drink – my wife still goes to weddings and parties with me, and she has a smashing time.

After I had a heart attack some years ago, my wife nursed me for two years. And now I'm nursing her in return. Often she takes my hand and tells me she loves me – and I get a lot of satisfaction out of seeing her happy. It's not always easy being a carer, but it is rewarding.

Good luck!

**JOE MCCALL**

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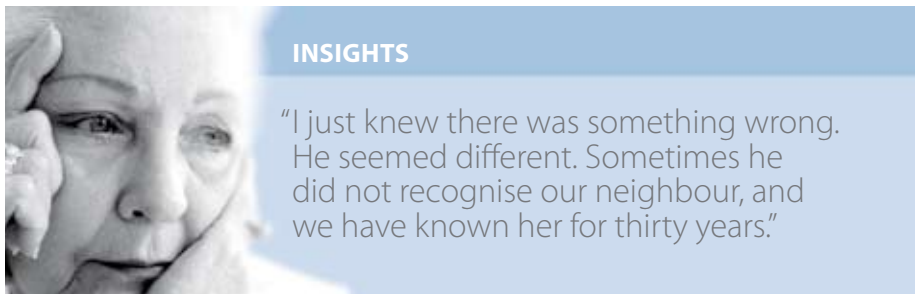
## ACKNOWLEDGEMENTS

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## INTRODUCTION

This booklet is for anyone who has become, or thinks they may become a carer for someone with dementia. Perhaps you think that someone close to you has dementia. Or maybe they have been given a diagnosis, and you are getting used to the idea of caring for them in the future. For many people, this can be a worrying time – you may be scared about how dementia will affect the person you are close to, and about the impact it may have on your own life.

Caring for someone with dementia is often demanding, but there are lots of places to go for help, and lots of information which can make sense of the experience. This booklet explains some of the basic facts about dementia, gives ideas on where you can get practical and emotional support, offers advice on how to plan for the future, and provides some tips on caring for people with dementia. Importantly, it also suggests some ways to look after yourself while you are caring. And finally, it recommends sources of further information and help. Once you have read this booklet, you may want to get in touch with some of these organisations.



### INSIGHTS

"I just knew there was something wrong. He seemed different. Sometimes he did not recognise our neighbour, and we have known her for thirty years."

## IS IT DEMENTIA?

### What is dementia?

The word dementia is used to describe a number of different conditions that affect the brain. Each of these conditions leads to a progressive decline in mental ability, such as memory loss, confusion, and problems with speech, concentration, thinking and perception.

### Who is likely to develop dementia?

Most people who develop dementia are over 65, although it does affect some younger people, usually in their forties and fifties (about one in a thousand). One in twenty people over 65 has dementia, and it affects one in five people over the age of 85. While dementia is most common in older people, it is not an inevitable part of ageing – the vast majority of older people remain mentally healthy.

### What forms of dementia are there?

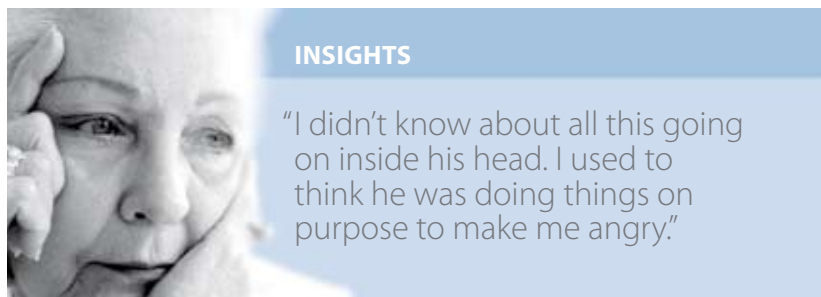
The most common types of dementia are Alzheimer's disease and vascular dementia. Although they have similar symptoms, they develop in different ways. Alzheimer's disease, which accounts for about 60 per cent of dementia, is characterised by changes in the structure of the brain, which causes brain cells to die. It usually starts gradually and progresses at a slow, steady pace. Vascular dementia occurs when a series of small strokes cut off the blood supply to parts of the brain. Unlike Alzheimer's disease, it often develops in sudden steps as these strokes happen.

## IS IT DEMENTIA? (CONTINUED)

Other, less common, types of dementia include: Lewy body disease (similar to Alzheimer's, although people with Lewy body disease are more likely to experience hallucinations – seeing, hearing, smelling or feeling things that aren't there – and physical difficulties, such as tremors and falls); Pick's disease (also known as frontal lobe dementia, referring to the part of the brain affected); Huntingdon's disease or Chorea (a rare form of dementia that usually develops at a younger age); and Creutzfeldt-Jakob Disease (the human form of 'mad cow disease', which is also very rare and thought to be linked to eating infected beef). Dementia can also occur as a result of Parkinson's disease, AIDS, a brain tumour, head injuries or alcohol misuse. Some of these rarer kinds of dementia can be treated – however, this booklet mainly looks at the most common forms, which are not currently curable (see Can dementia be treated?)

### What are the early symptoms of dementia?

The most common early sign is a loss of short-term memory – the person forgets things they have just said or done, even though they may clearly remember things that happened a long time ago. Sometimes people with early dementia say they feel they know something is wrong, but can't identify exactly what it is. Other symptoms vary, but tend to be noticed by others as 'odd' or 'uncharacteristic' behaviour, such as loss of interest in things the person enjoys, confusion, loss of skills and ability to do things they previously took in their stride, irregular sleeping patterns, reduced decision-making ability or mood swings.



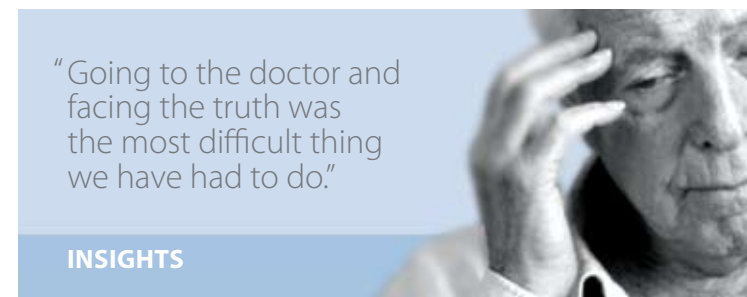
## IS IT DEMENTIA? (CONTINUED)

### Does dementia run in families?

Many people worry that if a relative of theirs has dementia, they will one day develop it too. Research suggests that there may be a genetic component to dementia, but that in most cases there is no clear family link. Instead, experts think that there may be a range of factors (including lifestyle, age, genetics, education and environment) which influence susceptibility to dementia. One exception is in families where several people have developed Alzheimer's disease before the age of 60, where a clear genetic connection, linked to faulty chromosomes, has been shown.

### Can dementia be treated?

Unfortunately, the most common types of dementia cannot be cured. Certain drugs may help reduce symptoms in the short term, although they do not work for everyone. However, dementia is not usually a direct cause of death, and people may live with the condition for many years. There are lots of ways of coping with dementia, and some of these are discussed in this booklet.



## FINDING OUT MORE

THE THOUGHT THAT SOMEONE YOU CARE ABOUT MAY HAVE DEMENTIA CAN BE FRIGHTENING. BUT IT IS USUALLY MUCH BETTER TO CONFRONT THAT FEAR AND TRY TO BE PRACTICAL ABOUT IT, IF YOU CAN. DEMENTIA-LIKE SYMPTOMS ARE SOMETIMES CAUSED BY OTHER TREATABLE CONDITIONS, SUCH AS DEPRESSION, THYROID PROBLEMS OR URINARY TRACT INFECTIONS. THAT IS ONE OF THE REASONS IT IS IMPORTANT THAT THE PERSON SEEKS MEDICAL ADVICE.

If you suspect someone you care for has dementia, contact their GP. A good GP will be able to carry out a full health check, discuss your concerns and the concerns of the person you care for, and, if necessary, refer them to specialists for further assessment. The person may also be referred to a memory clinic, where a team of specialists can help diagnose the problem and offer practical and emotional support.

It can take a long time to make a firm diagnosis, so you may need to be patient. Some doctors are reluctant to make a diagnosis until they can be totally sure the symptoms are not due to other causes. But any doctor should listen to your concerns, be prepared to investigate them fully (including making a referral to a specialist when appropriate), and review the situation regularly. If your GP is not helping as you would like, you do have the right to change doctor. If you can't find a new GP to take you on, your primary care trust must help you – contact NHS Direct on 0845 46 47 for more details. It is very important that the person you care for is informed at all times about what is happening. Research funded by the Mental Health Foundation has shown that people with dementia believe that it is much better to be told about their diagnosis than for information to be withheld from them. If they do have dementia, it will also give both of you a chance to plan for the future and to get the help and support you need.

## PLANNING FOR THE FUTURE

ONCE SOMEONE HAS BEEN DIAGNOSED WITH DEMENTIA, THEY AND THEIR CARERS USUALLY NEED TO PREPARE FOR SIGNIFICANT CHANGES IN THEIR LIVES. THIS SECTION EXPLAINS WHAT KIND OF PLANS YOU MIGHT NEED TO MAKE, AND TELLS YOU ABOUT THE PLACES YOU CAN GO FOR HELP.

### How far do we need to plan ahead?

Dementia often progresses slowly, and many people with a diagnosis live happy and fulfilling lives for a long time. But, whilst it can be a difficult subject to discuss, carers often say how important it is to make plans for the future with the person who has dementia. In the early stages, it is usually possible for the person to be fully involved, whereas later on this may not be possible.

One useful option is for the person with dementia to make an advance directive (also known as a 'living will'), which is a statement that sets out what they would like to happen if they are unable to make decisions in the future. This could include their preferences about nursing home care, what treatments they *do* and *don't* want, whether they want to be resuscitated in an emergency, and who they would like to make decisions on their behalf. Giving a copy of this plan to everyone involved (including the person's doctor) may help reassure the person that their wishes will be respected. If the person with dementia needs help with writing an advance directive, a solicitor will be able to advise them.

### Should I tell my employer about the diagnosis?

If you are working, and wish to continue, it is a good idea to inform your employer of the situation – they may be able to help you to carry on, perhaps with flexible hours. If you are unsure how your employer will react, it might be worth seeking advice from a carers' organisation. Some of these are listed at the end of this booklet (see section 6 – Useful Contacts).

## PLANNING FOR THE FUTURE (CONTINUED)

### Are there any legal issues that will need attention?

It may be necessary for the person with dementia to seek legal advice on choosing someone to take charge of their financial affairs when they are no longer able to do it themselves. As is the case with everyone, it is vital that they make a will, so that their wishes are respected when they die. A solicitor can help with granting power of attorney and making a will. If they drive, people with dementia have a responsibility to inform the DVLA (Drivers and Vehicles Licensing Authority) of their condition (contact them on 0870 6000 301). Having dementia does not necessarily mean a person will have to stop driving right away, although there will come a time when they will no longer be able to drive. Until then, a license can be issued on the understanding that it will be reviewed every year.

### What practical help can I get with caring?

Some people feel it's their duty to provide care alone, but there is professional help available – for example, social service departments can provide home care services, help with laundry and meals, and advice about safety aids (see Accessing Services). In some areas there are day care centres you and/or the person with dementia can attend. Caring for someone with dementia can be exhausting, so it is vital that you take breaks and get as much help and support as possible (see part four, Looking After Yourself). It can also be stimulating for people with dementia to socialise with others and enjoy a change of environment and activities. There are some organisations, such as Crossroads, The British Red Cross and For Dementia (see part 5 – Useful Contacts), which may be able to help with nursing care or providing safety equipment to fit around the house. Social services may also be able to advise on home adaptations.

## PLANNING FOR THE FUTURE (CONTINUED)

### Will I be able to get financial help while I am caring?

Caring for someone with dementia can have a big effect on your income, especially if you or they have had to give up work. If this happens, you may both be entitled to welfare or disability benefits, such as attendance allowance or the carer's allowance. To find out about benefits, call the Benefit Enquiry Line for people with disabilities on 0800 88 22 00, or contact your local Citizens Advice Bureau (see part five, Useful Contacts). Your social services office will also be able to assess you for ability to pay for the professional support they provide (see Accessing Services, below).

### What medical treatments will be prescribed to help the person I care for?

There are several drug treatments that are thought to relieve some of the symptoms of Alzheimer's disease, although they do not work for everyone, and they are not a cure. The most common of these are known as cholinesterase inhibitors, and include the drugs Aricept, Exelon, and Reminyl. The agency responsible for recommending which treatments doctors should prescribe, NICE, publishes guidance on the drugs that can be prescribed to relieve the symptoms of dementia. The guidance varies depending on whether someone has mild, moderate or severe dementia. For the latest information, please visit [www.nice.org.uk](http://www.nice.org.uk). Your GP or a specialist will advise you on which drugs may be suitable for the person you care for. People with Vascular dementia may be given drugs to thin the blood or correct irregular heartbeat, which may help reduce the risk of further strokes.

"You've got to keep calm and collected. Don't get angry. It's not easy, but it's rewarding if you just don't lose your temper."

INSIGHTS



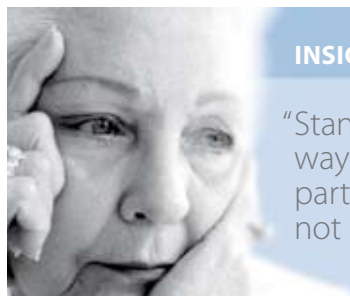
## PLANNING FOR THE FUTURE (CONTINUED)

### What other treatments might help people with dementia?

The GP will remain responsible for the person's general health, and should review their condition on a regular basis. They may also refer the person with dementia for specialist help, when they need it. Such help might come from a psychiatrist, community nurse, social worker, physiotherapist, occupational therapist, or continence advisor, and might involve practical nursing support, advice on coping with dementia and maintaining an active lifestyle, dietary planning or counselling. Some people with dementia are helped by reminiscence therapy, in which they are encouraged to recall events from the past. Others find complementary therapies such as acupuncture and aromatherapy useful.

### What will happen when the person with dementia can no longer be cared for at home?

There may come a time when caring for the person with dementia at home becomes too difficult, and they need to be moved to a residential home, either temporarily (known as respite care) or permanently. This is likely to be a difficult decision for carers and relatives, as well as the person with dementia, and issues such as payment can be complex, so it is important to consider it well in advance. Your local social services office will be able to advise on care homes in your area, and on whether you can get financial support.



#### INSIGHTS

"Standing up for yourself is the only way to get what you want. My partner deserves the best and I am not accepting anything less."

## ACCESSING SERVICES

UNFORTUNATELY, SERVICES FOR PEOPLE WITH DEMENTIA AND THEIR CARERS VARY GREATLY FROM AREA TO AREA. **BUT IT IS WORTH BEING PERSISTENT TO GET WHAT IS LEGALLY DUE TO YOU.**

Your local social services have a duty to assess you and the person with dementia for suitability and ability to pay for services such as day-care and home help, and to provide or pay for any help agreed on in the assessment. You and the person with dementia should receive separate assessments – carers' assessments are designed specifically to help identify services to support you as a carer. To arrange an assessment, call your local authority and ask to be put through to the social services office (if you live in Scotland, call your local council and ask for the social work department; if you live in Northern Ireland, contact your local Health And Social Services Trust). The assessment is likely to be carried out by a social worker who will be able to discuss your needs at length, and who will help work out what kind of support will be most helpful to you. This should be written up in the form of a care plan, and you should get a copy for your own records. Care plans should be reviewed regularly, so remember to ask when you will be due for further assessment.

"You need to know your rights when you are looking after someone with dementia, as sometimes other people don't. In the beginning, it's best to get help to find your way round systems and bureaucracy."

#### INSIGHTS



## THE EXPERIENCE OF CARING

IT CAN BE DIFFICULT TO COME TO TERMS WITH BECOMING A CARER FOR SOMEONE WITH DEMENTIA. NOT ONLY IS IT PAINFUL TO REALISE THAT SOMEONE YOU LOVE HAS DEMENTIA, BUT IT CAN ALSO BE HARD TO ACCEPT THAT YOUR LIFE MAY NEED TO CHANGE QUITE CONSIDERABLY. IT CAN BE DISTRESSING TO SEE CHANGES IN THE ABILITIES OF A LOVED ONE, AND FRUSTRATING TO FEEL AS IF YOU ARE LESS ABLE TO COMMUNICATE WITH THEM THAN BEFORE. YOU WILL SEE CHANGES IN THEIR ABILITIES OVER TIME, AND THIS MAY MAKE YOU FEEL SAD. BUT ALTHOUGH CARING IS NOT EASY, SOME PEOPLE SAY IT CAN BRING UNEXPECTED REWARDS, SUCH AS AN OPPORTUNITY TO SHOW HOW MUCH THEY LOVE THE PERSON THEY ARE LOOKING AFTER.

### What kind of problems will someone with dementia experience?

People with dementia tend to experience problems with their mental ability (memory, thinking, concentration and perception), which then affects their behaviour. Dementia can reduce a person's ability to carry out everyday tasks, such as washing, going to the toilet, getting dressed, cooking or cleaning. They may forget to do things, repeat tasks they have already completed, or do them at an unusual time or in an 'odd' way. They may have trouble holding conversations, making decisions, understanding what is said to them or expressing how they feel. Or they may have trouble remembering people's names, dates or everyday words, and become less physically co-ordinated. They may also become frustrated at not being able to communicate or carry out tasks as well as they would like.

Some people with dementia seem calm, quiet, and happy, while others seem more irritable, difficult to live with, or distracted. Sometimes they may suffer from other problems as a result of living with dementia, such as depression. Of course, not everyone with dementia will experience all of these difficulties, and every person will continue to experience them in their own way.

## EXPERIENCE OF CARING (CONTINUED)

The speed of onset and severity of the illness varies considerably, and symptoms will also vary, even from day to day. In the early stages, many people continue to live a fairly independent life. However, problems are likely to become more severe as the illness progresses, and later on, people with dementia become severely incapacitated, both physically and mentally. They often experience severe memory loss, are sometimes unable to recognise familiar people, places or objects, and may have severe problems with basic functions like walking, talking or eating. One of the most distressing aspects of the disease is that in its later stages, the person with dementia may no longer be able to remember your name or to recognise you physically. However, at an emotional level they will continue to know you as someone they have loved and cared about for many years. By this stage, they may become completely dependent on others to care for them.

### How can I be most helpful to the person with dementia?

It is very important to remember that the person with dementia remains an adult in their own right. Having a diagnosis of dementia does not take their humanity away from them, and indeed, for a long time they may be able to live a relatively independent life. The best way to support them is to continue to treat them with respect and dignity, and to listen to and try to understand their experience. They will still express their thoughts and emotions, although as time passes you may need to learn to understand them and communicate with them in a new way. Even though they have a disability, it is important to remember that they will not want to be treated like a child. Encourage them to carry out daily tasks on their own and continue to do things which they have always enjoyed. Having dementia may change what a person can manage over time, but it will still be possible to celebrate and support what they can do.



## EXPERIENCE OF CARING (CONTINUED)

### What is the best way to respond to 'unusual' behaviour?

Some people feel hurt, embarrassed or angry when a loved one with dementia behaves in a 'strange' way, but it is vital to remember that this is an effect of the illness. It can be tempting to try and avoid difficult situations by shielding the person with dementia from others – unfortunately, this can lead to both you and them becoming isolated. It may be better to explain the situation to people – when they understand that the person has dementia, they may well be far more understanding, or even offer to help.

Getting into arguments about 'odd' things the person is saying or doing is not usually a good idea – it may be better to distract their attention to another subject so as to avoid confrontation. And although it may be unsettling, embarrassing or irritating to you, some unusual behaviour may well be best left unchallenged – especially if there is no physical danger in what the person is doing, and they do not seem distressed by it. Whatever response you decide on, being calm, gentle and understanding is usually the best way to help a person with dementia.

### How should I communicate with someone who has dementia?

As with any relationship, the key to success is listening, understanding, being supportive and making a real effort to connect with the other person's experience. We all need to feel cared for and understood – and people with dementia are no different. One of the most important skills to learn when being with someone with dementia is to realise that when their thinking skills aren't working as well, they may rely heavily on their emotions to express themselves. Paying attention to non-verbal signs of emotion can help you listen to and communicate with them more effectively (see Maintaining A Relationship With Someone Who Has Dementia).

## MAINTAINING A RELATIONSHIP WITH SOMEONE WHO HAS DEMENTIA

HERE ARE SOME IDEAS WHICH MAY HELP MAINTAIN AND IMPROVE YOUR RELATIONSHIP WITH SOMEONE WHO HAS DEMENTIA:

- If you are experiencing problems with communication, remember to speak clearly and slowly, using straightforward language. Allow the person with dementia time and space to respond and be prepared to repeat things if necessary. Eye contact, physical touch and careful listening can all show someone we are hearing what they are saying.
- In the early stages of dementia, a person's abilities are likely to remain intact. It is important not to patronise them, or treat them as if they are less capable than they really are. Keep things normal for as long as possible and carry on doing things that you both enjoy.
- Although a person with dementia's communication skills will be affected over time, their words and actions will still have a meaning. It is crucial to listen to and attempt to understand their words and actions, perhaps even more closely than we would with any other person.
- Get to know as much as you can about dementia. This booklet gives a broad overview of the condition, and there is a list of sources of further information in section six. The more you know, the better you will be able to help and care for the person you love.
- Focus on what the person can do, rather than what they can't. Keeping positive will help both you and them enjoy life.
- Don't get into arguments about the 'reality' of what they are experiencing. Even if you think that they are mistaken, listen to what they are saying rather than simply contradicting them – this demonstrates your understanding that what they are experiencing is real to them, and will help them to feel acknowledged and valued.
- Don't attempt to test their memory or pressurise them in any way. Remind them how much you care about and love them, no matter what their abilities are – this will show them you accept them as they are.
- Although safety is important, don't restrict their freedom more than is absolutely necessary. Allowing people to keep as much independence as possible helps them to feel they have some control over their lives.
- Try to help them follow a daily routine. This can stimulate their memory, reduce confusion and help keep you and them feeling calm and balanced. Similarly, keeping decisions simple and breaking down tasks into lots of small steps can reduce the chances of you and the person with dementia becoming overwhelmed. Using memory aids – such as pictures of family and friends, or a notebook and diary in which reminders can be written – may also help stimulate their memory.

## LOOKING AFTER YOURSELF

ONE OF THE MOST IMPORTANT WAYS THAT CARERS CAN HELP PEOPLE WITH DEMENTIA IS TO ENSURE THAT THEY TAKE CARE OF THEMSELVES AS WELL. BEING A SUPPORT FOR SOMEONE WITH DEMENTIA CAN BE EXHAUSTING, AND WHILE MANY CARERS FEEL THEY HAVE TO SPEND THEIR ENERGY ON THE PERSON THEY ARE CARING FOR, IT IS IMPORTANT TO REALISE THAT YOU TOO NEED LOOKING AFTER. HERE ARE SOME OF THE WAYS TO ENSURE YOU TAKE CARE OF YOURSELF:

**1. Take regular breaks** While it may be tempting to focus all your efforts on the person with dementia, you are more likely to be able to support them if you can take time out to recharge your batteries, see friends, carry out tasks like shopping and cleaning, or pursue interests and hobbies. Keeping up other activities away from care work can also prevent you from becoming isolated. Friends or family may be willing to help share duties, and many carers find the respite provided by day services valuable. If you are struggling to find ways to take a break, talk to your GP or social services – they may be able to help you take some time out.

**2. Talk to other people** Caring for someone with dementia can bring up distressing feelings, as well as being very hard work. Most carers find it an enormous relief to be able to talk about their experiences with other people. Support groups for carers exist in most areas – these are places where you can meet people who are going through similar experiences, get advice on care, share stories and make new friends. Organisations such as The Alzheimer's Society, Age Concern and Carers UK run helplines which you can call for advice – they may also be able to help put you in contact with a local support group (see part 6, Useful Contacts). Staying in touch with family and friends can also provide an important source of support. If you are finding it hard to cope, you may also find it helpful to talk to a community nurse, counsellor or clinical psychologist – ask your GP if s/he can make an appointment for you. Different tasks in the caring relationship affect people in different ways; some things you may deal with easily, others you may find hard. The experience will be different for different people.

## LOOKING AFTER YOURSELF (CONTINUED)

**3. Be kind to yourself** Sometimes carers say it is hard not to feel guilty about their situation. You may feel you are not doing as well as you should be, or are letting the person with dementia down if you get angry or upset. But nobody is perfect, and caring can be an extremely difficult job. Remember to congratulate yourself for the hard work you are doing, and that you are doing your best for someone you love. If you are struggling to cope, there is absolutely nothing wrong with seeking help – from family, friends, social services, support groups or your GP. When someone is in the final stages of dementia, you may feel that your loved one has already passed away, and that you can no longer offer much care. Different people cope in different ways, but it is important to remember that these feelings are normal. Counselling may help you deal with guilt, bereavement or anger.

**4. Look after your health** Being a carer can put a big strain on your health. In order to be a support to the person with dementia, it's vital to look after yourself, both mentally and physically. Taking regular exercise, eating a well-balanced diet, getting plenty of sleep, and taking time out each day for some relaxation will all help you stay well. Contact your GP if you are feeling ill or stressed.

## A FINAL THOUGHT ABOUT CARING FOR SOMEONE WITH DEMENTIA

From reading the above, it may seem that caring for someone with dementia is a daunting and difficult task. And while it is true that some people find caring to be exhausting and painful at times, many also say that there are also lots of good things to be drawn from the experience, and that remembering these can help make the job easier. Positive things carers have mentioned include:

- **The opportunity to show their love for and commitment to a relative or friend by caring for them.**
- **The satisfaction of surviving and succeeding in the face of adversity.**
- **Becoming emotionally closer to family, friends and the person with dementia through the shared effort of caring.**
- **Meeting new people who are going through similar experiences.**
- **The realisation that every day living with the person with dementia is precious, and that even though things may have changed, they can still enjoy happy times with them.**

## USEFUL CONTACTS

BECOMING A CARER HAS PROVIDED AN OVERVIEW OF INFORMATION ABOUT CARING FOR SOMEONE WITH DEMENTIA. THIS SECTION TELLS YOU ABOUT SOME OF THE MANY PLACES THAT OFFER HELP, ADVICE AND INFORMATION..

### AGE CONCERN ENGLAND

Astral House  
1268 London Rd  
London SW16 4ER

**020 8765 7200**

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

**Helpline: 0800 00 99 66**

Provides advice on a variety of older peoples' issues, such as benefit entitlements and legal concerns. Can also help you find local support groups. Helpline open 7am-7pm every day.

### AGE CONCERN SCOTLAND

113 Rose Street  
Edinburgh EH2 3DT

**0131 220 3345**

<http://www.ageconcernscotland.org.uk>

### AGE CONCERN NORTHERN IRELAND

3 Lower Crescent  
Belfast BT7 1NR

**028 9024 5729**

### AGE CONCERN CYMRU

4th Floor  
1 Cathedral Road  
Cardiff CF11 9SD

**029 2037 1566**

<http://www.accymru.org.uk>

### ALZHEIMER SCOTLAND – ACTION ON DEMENTIA

22 Drumsheugh Gardens  
Edinburgh EH3 7RN

**0131 243 1453**

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

[Alzheimer@alzscot.org](mailto:Alzheimer@alzscot.org)

**Helpline: 0808 808 3000**

Scotland's leading charity for people with dementia and their carers. Helpline open 24 hours.

### BENEFIT ENQUIRY LINE

**Helpline: 0800 88 22 00**

Deals with benefit enquires for people with disabilities and their carers.

Open 8.30am-6.30pm  
Mon-Fri. 9am-1pm Sat.

### THE ALZHEIMER'S SOCIETY

Gordon House  
10 Greencoat Place  
London SW1P 1PH

**020 7306 0606**

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

[enquiries@alzheimers.org.uk](mailto:enquiries@alzheimers.org.uk)

**Helpline: 0845 300 0336**

The leading UK care and research charity devoted to people with dementia and their carers. Produces an extensive range of fact sheets on all aspects of dementia, including caring for people with dementia, and runs a national network of support groups and other services for carers through its local branches. Its helpline is open 8.30am-6.30pm Monday to Friday, offering advice, information and support for everyone affected by dementia. Its website features a chatroom for people to exchange thoughts and feelings.

## USEFUL CONTACTS (CONTINUED)

### BRITISH RED CROSS

44 Moorfields  
London EC2Y 9AL

**0870 170 7000**

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

Offers crisis respite sitting services for carers who need to take a break.

### CARERS UK

20-25 Glasshouse Yard  
London EC1A 4JT

**020 7490 8818**

**Helpline: 0808 808 7777**

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

Provides advice and information for carers on a wide range of topics. The only UK carer-led organization working for all carers.

### FOR DEMENTIA

6 Camden High Street  
London NW1 0SH

**020 7241 8555**

**Tel: 020 7874 7210**

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

Promotes nursing care for people with dementia, and runs a carers' network.

### COUNSEL AND CARE

Twyman House  
16 Bonny Street  
London NW1 9PG

**020 7241 8555**

**Advice line: 0845 300 7585**

Open 9am-12pm & 2pm-4pm Mon-Fri. Advice and information service for older people, their carers, relatives and professionals working with them.

### CARING MATTERS

132 Gloucester Place  
London NW1 6DT

**020 7402 2702**

[www.caring-matters.org.uk](http://www.caring-matters.org.uk)

[info@caring-matters.org.uk](mailto:info@caring-matters.org.uk)

Offers information for carers, on topics such as advocacy, financial and legal matters, finding home help or care homes, coping with caring.

### CITIZEN'S ADVICE BUREAU

Myddleton House  
115-123 Pentonville Rd  
London N1 9LZ

**020 7833 2181**

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

Helps people resolve their legal, money and other problems by providing free information and advice from over 3,200 locations.

### CROSSROADS CARE SCHEMES

10 Regent Place  
Rugby

Warwickshire CV21 2PN

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

**01788 573653**

Offers support for carers in the home. Trained workers provide free home care, enabling the carer to take time off.

## USEFUL CONTACTS (CONTINUED)

**DEPARTMENT OF HEALTH**

Richmond House  
79 Whitehall  
London SW1A 2NL

**0207 210 4850**

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

UK Government department with responsibility for health. Produces Who Cares?, a useful information guide for carers of people with dementia.

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**THE HUNTINGDON'S DISEASE ASSOCIATION**

108 Battersea High St  
London SW11 3HP

**Tel: 020 7223 7000**

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

Exists to support people affected by Huntingdon's disease and to provide information and advice to professionals whose task it is to support Huntington's disease families in the UK.

**THE MENTAL HEALTH FOUNDATION**

Sea Containers House  
20 Upper Ground  
London SE1 9QB

**020 7803 1100**

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

[mhf@mhf.org.uk](mailto:mhf@mhf.org.uk)

The leading UK charity working in mental health and learning disabilities. Undertakes research, develops services, designs training, influences policy and raises public awareness about all aspects of mental health and learning disabilities, including dementia.

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**NHS DIRECT**

**Helpline: 0845 46 47**

Health information and advice service. Open 24 hours a day.

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**THE PRINCESS ROYAL TRUST FOR CARERS**

142 Minories,  
London EC3N 1LB

**020 7480 7788**

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

A network of carers' centres, providing information, support services and practical help.

**PARKINSON'S DISEASE SOCIETY**

215 Vauxhall Bridge Road  
London SW1V 1EJ

**020 7963 9380 (chk)**

**Helpline: 0808 800 0303**

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

Provides specific information and advice about Parkinson's disease. Helpline open 9.30am-5.30pm Mon-Fri.

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**SAMARITANS**

**Helpline: 8457 90 90 90**

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

Confidential emotional support for people who are experiencing feelings of distress or despair, including those which may lead to suicide. Helpline open 24 hours a day.

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**WINGED FELLOWSHIP TRUST**

Angel House  
20-30 Pentonville Road  
London N1 9XD

**020 7833 2594**

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

Provides information about supported holiday sites for people with disabilities.

**SOLICITORS FOR THE ELDERLY**

PO Box 257  
Broxbourne  
Hertfordshire EN10 7YY

**01992 471568**

(9am-1pm Mon-Fri)

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

National association of solicitors, barristers and legal executives who are committed to providing comprehensive, independent legal advice for older people, their family and carers.

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**THE STROKE ASSOCIATION**

Information Service  
Stroke House  
240 City Road  
London EC1V 2PR

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

**Helpline: 0845 303 3100**

National organisation that provides support, written information and local support for people who have had strokes. Helpline open 9am-5pm Mon-Fri.

This booklet explains some of the **basic facts** about **dementia**, gives **ideas** on where you can get **practical** and **emotional** support, offers **advice** on how to plan for the **future**, and provides some tips on **caring** for **people** with dementia.

Mental Health Foundation

**Published by the Mental Health Foundation, August 2005**

For more information about dementia, please visit [www.mentalhealth.org.uk](http://www.mentalhealth.org.uk)

To order additional copies of this booklet please email [mhf@mhf.org.uk](mailto:mhf@mhf.org.uk)

Sea Containers House, 20 Upper Ground, London SE1 9QB

Tel: 020 7803 1100 Fax: 020 7803 1101

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

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