Still going strong

A guide to living with DEMENTIA

Mental Health Foundation

FOREWORD

After the shock of being given a diagnosis of dementia, you could be excused for thinking that your life has come to an end, and that there is no hope for what lies ahead. It can seem like you are staring at a bleak, dark hole of a future.

I know - I've been there. And I can reassure you that, however it may feel at the beginning, it is still possible to live a life of quality with dementia. Not the life you had before, perhaps, but a life full of promise.

Perhaps you are reading this booklet because you think you may have dementia and want to find out more. Or perhaps you already have a diagnosis and are looking for ways you can get help and continue to live a happy life. Either way, take heart. If you do have dementia, you will still be able to do many things you did before by yourself, and others you will be able to manage with a little assistance. You may even find time to return to old hobbies or to learn to do things you always wished you'd had time for. It is a time for opportunity which you should grab with both hands.

I no longer feel isolated and alone. I have made many new friends, including many who support me, and of course, others with dementia. We are a great bunch of people.

This booklet tells you that "people with dementia often live happy, fulfilling lives for many years after they have been diagnosed". If you take a positive outlook and are determined to get on with life as best you can, I think you will be pleasantly surprised at what you can achieve. I certainly know many positive people who fall into that category.

I sincerely hope that if you do have dementia, you come to be one of them.

JAMES MCKILLOP

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INTRODUCTION

This booklet is for people who want to find out more about living with dementia. Perhaps you have recently been told you have dementia, and want to know more about what this might mean for you and those around you. Or maybe you have been experiencing problems which you think may be due to dementia, and want to learn more about it, how it affects people and where to go for help.

For many people, this can be a worrying time – you might be scared about having dementia, and about the impact it may have on those close to you. And while it is true that having dementia can be challenging, there are many ways you can get help, and lots of information to help you make more sense of the experience.

This booklet explains some of the basic facts about dementia, gives ideas on where you can get practical and emotional help, offers advice on planning for the future, and details some strategies which other people have used to cope with dementia. Finally, it recommends places to go for information and help for people with dementia. Once you have read this booklet, you may want to get in touch with some of these organisations.



INSIGHTS

"The more I know, the better I have been able to cope. I don't feel so frightened."

IS IT DEMENTIA?

MANY OLDER PEOPLE WORRY THAT THEY MAY DEVELOP DEMENTIA. HOWEVER, THERE IS A BIG DIFFERENCE BETWEEN NORMAL FORGETFULNESS, WHICH HAPPENS TO ALL OF US AT TIMES, AND DEMENTIA. THIS SECTION EXPLAINS SOME OF THE BASIC FACTS ABOUT DEMENTIA, AND HOW YOU CAN FIND OUT MORE IF YOU ARE WORRIED.

What is dementia?

The word dementia is used to describe a number of different conditions that affect the brain. Each of these leads to a 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 one in five over the age of 85. But while dementia is most common in older people, it is not an inevitable part of ageing – the vast majority of older people stay mentally healthy.

IS IT DEMENTIA? (CONTINUED)

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 linked to 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 happens when a series of small strokes cuts off the blood supply to parts of the brain. Unlike Alzheimer's disease, it often develops in sudden steps as these strokes happen.

Other, less common, types of dementia include: Lewy body disease (similar to Alzheimers, 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 Creutzfeld 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 happen as a result of Parkinson's disease, AIDS, a brain tumour, head injuries or alcohol misuse. Some of these can be treated, which is one reason why it is important to get medical help if you think you may have dementia. However, this booklet looks at the most common forms of dementia, which are not currently curable (see next page , can dementia be treated?)



INSIGHTS

"Learning about dementia has taught me how to live my life again. I am not going to let it control me."

IS IT DEMENTIA? (CONTINUED)

What are the early signs of dementia?

The most common early sign of dementia is a loss of short-term memory – you may sometimes forget things you have just said or done, even though you clearly remember things that happened a long time ago. Other signs might include losing interest in things you used to enjoy, finding it difficult to do everyday things you previously took in your stride, confusion, sleeping badly or at unusual times, difficulty with making decisions or feelings of depression. Some people with early dementia say they know something is wrong, but can't identify exactly what it is. Others say that they feel like they are living under a cloud. People around you may experience some things you say or do as 'odd' or 'uncharacteristic'. However, just because you are having some symptoms – forgetfulness, say, or low mood – this does not necessarily mean you have dementia.

Can dementia be treated?

Unfortunately, the most common forms of dementia can't be cured. Drugs may help reduce the effects in the short term, but they don't work for everyone. But people often live with dementia for many years, and it is not usually a direct cause of death. And while there is no cure for dementia, there are lots of ways of coping. Some of these are discussed in this booklet.



FINDING OUT MORE

THE THOUGHT THAT YOU MAY HAVE DEMENTIA CAN BE FRIGHTENING. BUT IT'S USUALLY MUCH BETTER TO CONFRONT THAT FEAR, AND TRY TO BE PRACTICAL ABOUT DEMENTIA, IF YOU CAN. DEMENTIA-LIKE SYMPTOMS ARE SOMETIMES CAUSED BY OTHER TREATABLE CONDITIONS, SUCH AS DEPRESSION, THYROID PROBLEMS OR URINARY TRACT INFECTIONS, SO IT IS ALWAYS WORTH SEEKING MEDICAL ADVICE. IF YOU DO HAVE DEMENTIA, IT WILL GIVE YOU AND THOSE YOU LOVE A CHANCE TO PLAN FOR THE FUTURE AND GET THE HELP AND SUPPORT YOU WILL NEED.

The first thing to do if you think you have dementia is contact your GP. A good GP will be able to discuss your concerns, carry out a full health check, including an examination of your memory, and, if necessary, refer you to specialists for further help. It can be a good idea to take someone you trust with you when you go to the doctor – they can support you in explaining your worries, and perhaps write down notes of the plan agreed by you and your doctor. Some people also find it helps to write down questions for the doctor beforehand, so that they do not forget them when they are in the surgery.

It can take a long time to make a firm diagnosis, so you may need to be patient. Some doctors are reluctant to diagnose dementia 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 if necessary), and agree to review your situation regularly. They may also refer you to a memory clinic, where a team of experts can give you practical and emotional support.

Most people with dementia say it is important to them to know as much as possible about their condition, and you can insist that your doctor keeps you fully informed. If your GP is not helping as you would like, you do have the right to change doctor. And 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.

LIVING WITH DEMENTIA

IT'S NOT EASY TO COME TO TERMS WITH HAVING DEMENTIA. IT CAN BE PAINFUL TO FIND OUT THAT YOU HAVE A CONDITION THAT CAN'T BE CURED, AND PERHAPS HARD TO ACCEPT THAT YOUR LIFE MAY NEED TO CHANGE A LOT OVER TIME. YOU MIGHT FEEL FRUSTRATED AT NOT BEING ABLE TO COMMUNICATE AS WELL AS YOU USED TO, AND SAD AT THE PROSPECT OF HAVING TO GIVE UP DOING THINGS YOU ENJOY. BUT SOME PEOPLE SAY THAT HAVING DEMENTIA CAN BRING UNEXPECTED REWARDS, SUCH AS BRINGING THEM CLOSER TO LOVED ONES, OR PROVING HOW STRONG THEY ARE IN THE FACE OF DIFFICULTIES. THIS SECTION EXPLAINS MORE ABOUT HOW DEMENTIA CAN AFFECT YOU, AND HOW PEOPLE WITH DEMENTIA COPE WITH THE CONDITION AND CONTINUE TO LIVE THEIR LIVES.

How might having dementia affect me?

You may sometimes forget to do things, repeat tasks you have already completed, or do, say and see things in a way that other people might think is unusual or 'odd'. You may find it harder to keep up with conversations, make decisions, and express how you feel. You might have trouble remembering people's names, dates or everyday words, or become less physically co-ordinated. Over time, dementia can reduce your ability to carry out everyday tasks, such as washing, going to the toilet, getting dressed, cooking or cleaning. However, not everyone with dementia will have all of these difficulties, and every person will experience them in their own way.

" It's not always easy, but knowing I have friends and a family who love me helps. They are very proud of me, they tell me."

INSIGHTS

LIVING WITH DEMENTIA (CONTINUED)

How quickly will the dementia progress?

It varies from person to person. In many cases, the progression is slow, giving you time to adjust to changes in your abilities, although symptoms will probably vary from day to day. In the early stages of dementia, many people continue to live fairly independent lives. Problems are likely to become more severe as the illness progresses, and later on, people can become severely affected, both physically and mentally. People with later stage dementia often experience severe memory loss, are sometimes unable to recognise familiar people, places or objects, and may have problems with basic things like walking, talking or eating. By this stage, they may become completely dependent on others to care for them. But it is important to remember that many people with dementia live happy and fulfilling lives for years after their dementia has been diagnosed.

What should I say to friends and family about having dementia?

Many people find it difficult to tell those around them that they have dementia. Some feel they would be judged or overprotected if other people knew about their dementia, while others say that that they don't want people to worry about them. Some don't want to 'rock the boat', preferring to keep things as 'normal' as possible. However, it is usually best to tell people you love about having dementia. Being honest increases the chances of getting as much support as possible, while those people around you are more likely to be understanding and helpful if they know what is going on. You could also tell them about your fears, and explain carefully how they can best be helpful.

LIVING WITH DEMENTIA (CONTINUED)

I feel angry and scared about having dementia. Is this normal?

Yes. People experience many different emotions when they find out they have dementia. These can range from shock and disbelief to fear, anger, sadness and despair. It can take time to adjust to the idea of having dementia, and while difficult feelings are not pleasant, they are normal. If you are finding it hard to cope, speak to your GP. He or she may be able to refer you to a community nurse, counsellor or psychologist, who can help you work through your feelings.

I'm worried that other people will start treating me like a child just because I have dementia. What can I do?

Having dementia does not mean that you are any less an adult. You have a right to be treated with respect and dignity, and to be listened to and understood. However, sometimes people close to someone with dementia may try to overprotect them or assume that they are less capable than they really are. If this happens, talk to them about how you are feeling, and how you would like them to help you live with dementia. Carers of people with dementia could read our booklet, Becoming A Carer, which explains more about how to offer care and relate to people with dementia.

What can I do to stay healthy and look after myself?

It is important that, as far as possible, you continue to carry out daily tasks and do things which you have always enjoyed. Don't give up on life – even if you have decided to stop doing some things that used to occupy you (such as work), you may be able use your time to learn new skills, or take on volunteer work. It's important to stay positive and to look after yourself – by taking regular exercise for example, and eating healthily. Having dementia may change what you can manage over time, but you can still choose to make the most of and enjoy what you can do.

LIVING WITH DEMENTIA (CONTINUED)

What kinds of support can I ask for?

There are many different kinds of help available for people with dementia. It can be difficult to depend on others, or to ask for support, especially if you are used to taking full responsibility for yourself. But asking for help when you need it can be a sign of strength, and it might be easier to live independently when you have the support of others.

Many people with dementia ask their friends and family to help them – and indeed, some report that doing this can bring them closer together. You can ask your GP to monitor your health on a regular basis, and your local social services department may be able to provide help around the home – such as with laundry, meals and safety aids – and a place to go during the day, such as a day centre. (see section 4: Accessing Services). Several voluntary organisations offer practical help (see Section 5: Useful Contacts), and some also run helplines you can call for advice, support and help. For example, you can call the Alzheimer's Society helpline on 0845 300 0336, and Age Concern on 0800 00 99 66.

You might also find it helpful to join a support group for people with dementia. Support groups are places where you can meet people who are going through similar experiences, get advice on coping with dementia, share stories and make new friends. Having dementia can bring up distressing feelings, and most people find it an enormous relief to be able to talk about their experiences with other people who know what they are going through.



STRATEGIES PEOPLE WITH DEMENTIA HAVE FOUND HELPFUL

- Follow a daily routine. This can stimulate your memory and help you feel calm and balanced. If there are regular things you need to remember, like locking doors or taking medication, write them on a notice board and pin them up somewhere prominent.
- Go easy on yourself. It's OK to take your time over essential tasks that you might have done more easily in the past. It's also fine to ask someone to repeat themselves if you haven't understood or have forgotten something they said.
- Carry a notebook with lists of people's names, telephone numbers and daily tasks written inside you can refer to it if you have trouble remembering things.
- Stay in touch with friends and family. Maintaining a social life can help prevent you from becoming isolated.
- Keep important items, like keys, spectacles or your notebook, in the same place, so you get in the habit of knowing where to look for them.
- Write telephone numbers of important people your friends, family, GP, and care staff (such as your CPN) on a pad near the phone.
- Focus on what you can do, rather than what you can't Keeping positive will help you enjoy life.
- Ask your bank to set up direct debits to pay all your important bills, so that you don't need to worry about them.
- Remember that dementia is a disability. It is not your fault if you have difficulty remembering things or doing things which used to seem easy. Don't worry what other people think it is their problem if they cannot deal with your disability.
- Carry a card which tells people that you have dementia. This can be useful if you get into a difficult situation and need someone to help you. Include the telephone number of someone you trust who can be called if necessary.
- Get to know as much as you can about dementia. This booklet gives a broad overview, and there is a list of places to get further information in section five. The more you know, the more you will feel able to cope

PLANNING FOR THE FUTURE

PEOPLE WHO HAVE DEMENTIA OFTEN WORRY ABOUT WHAT WILL HAPPEN TO THEM IN THE FUTURE. YOU MAY BE CONCERNED ABOUT HOW YOU WILL BE CARED FOR AS THE DEMENTIA GETS WORSE, HOW YOU CAN BE SURE THAT YOUR MONEY AND OTHER ASSETS WILL BE LOOKED AFTER AS YOU WISH, AND WHAT PRACTICAL AND MEDICAL HELP YOU CAN GET. THIS SECTION IS ABOUT SOME OF THE PLANS YOU MAY NEED TO MAKE, AND THE PLACES YOU CAN GO TO FIND HELP.

How far do I need to plan ahead?

While it can be a difficult subject to discuss, people with dementia often say how important it is to make plans for the future. Having definite plans for your care arrangements, medical treatments and finances can bring peace of mind. Also, in the early stages of dementia, it is usually possible to be fully involved in the planning process, whereas later on this may not be possible. One option to consider is making an advance directive (also known as a 'living will'). This is a statement that sets out what you would like to happen if you are unable to make decisions in the future. This could include your preferences about nursing home care, what treatments you do and don't want, whether you want to be resuscitated in an emergency, and who you would like to make decisions on your behalf. Giving a copy of this plan to everyone involved (including your GP and solicitor) can help reassure you that your wishes will be respected. If you need help with writing an advance directive, a solicitor will be able to advise you.



PLANNING FOR THE FUTURE (CONTINUED)

Should I tell my employer that I have dementia?

If you are working, and wish to continue, it is vital to inform your employers of the situation – they may be able to help you to carry on, perhaps with flexible hours, or with different responsibilities. Sometimes employers can get financial support to help keep you in your job. The Disability Employment Advisor at your job centre can advise you about this. If you are unsure about how your employer will react, it may be worth seeking advice from one of the specialist organisations that help people with dementia. Some of these are listed at the end of this booklet'.

Are there any legal issues that will need attention?

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

PLANNING FOR THE FUTURE (CONTINUED)

What practical help can I get?

Social service departments can provide home care services, help with laundry and meals, and advice about safety aids (see Accessing Services, below). In some areas there are day care centres you can attend. 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.

Will I be able to get financial help?

Having dementia can have a big effect on your income, especially if you have had to give up work. If this happens, you may be entitled to welfare or disability benefits, such as Attendance 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 can be prescribed?

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 Your GP or a specialist will advise you on which drugs may be suitable for you. 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.

PLANNING FOR THE FUTURE (CONTINUED)

What other treatments might help me?

Your GP will also remain responsible for your general health, and should review your condition regularly. Your GP may also refer you for specialist help when you need it. Such help might come from a psychiatrist, community nurse, social worker, physiotherapist, clinical psychologist, occupational therapist, or continence advisor, and might involve practical nursing support, advice on coping with dementia and maintaining an active lifestyle, helping protect against other illnesses, 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 if I can no longer live at home?

There may come a time when living at home becomes too difficult, and you may need to move to a residential home, either as a temporary measure or permanently. This is likely to be a difficult decision for you and those around you, and issues such as payment can be complex, so it is important to consider it well in advance – especially so you can have a say in how and where you might be cared for. Your local social services office will be able to advise on care homes in your area, and on whether you can get financial support.

"I needed to know that I was not the only one. Finding out about dementia and reading what other people say has really helped. I don't feel so alone now."



INSIGHTS

ACCESSING SERVICES

UNFORTUNATELY, SERVICES FOR PEOPLE WITH DEMENTIA 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 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. To arrange an assessment, call your local council and ask to be put through to the social services department, who will be able to advise you on arranging an assessment (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 you should ask when you will be due for further assessment. If you have a carer, they also have a right to a separate assessment for services that might help them.



INSIGHTS

"Dementia has affected my whole family, but we have decided we are in this together now and we have to work it out. Now they understand I am really the same person."

A FINAL THOUGHT ABOUT LIVING WITH DEMENTIA

LIVING WITH DEMENTIA MIGHT SEEM LIKE A DIFFICULT PROSPECT. AND WHILE IT IS TRUE THAT HAVING A CONDITION SUCH AS DEMENTIA AND GOING THROUGH CHANGES IN YOUR ABILITIES OVER TIME CAN BE DISTRESSING, MANY PEOPLE SAY THAT THERE ARE ALSO LOTS OF GOOD THINGS TO BE DRAWN FROM THE EXPERIENCE.

People with dementia have highlighted such positive factors as:

- The satisfaction of surviving and succeeding in the face of adversity.
- Becoming emotionally closer to family and friends through sharing the experience of dementia with them.
- Meeting new people who are going through similar experiences.
- The realisation that every day is precious, and that even though things may have changed, they can still enjoy happy times.

"One day I couldn't take it anymore and I made my wife ring a helpline and someone came to see us. It was the best thing I ever did – we haven't stopped talking since."



USEFUL CONTACTS

STILL GOING STRONG HAS PROVIDED A BRIEF OVERVIEW OF THE EXPERIENCE OF LIVING WITH DEMENTIA. THIS SECTION TELLS YOU ABOUT SOME OF THE MANY SOURCES OF SUPPORT AND INFORMATION YOU CAN CONTACT FOR FURTHER HELP, ADVICE AND INFORMATION.

AGE CONCERN ENGLAND

Astral House 1268 London Rd London SW16 4ER 020 8765 7200 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

Alzheimer@alzscot.org Helpline: 0808 808 3000

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

THE ALZHEIMER'S SOCIETY

Gordon House 10 Greencoat Place London SW1P 1PH 020 7306 0606 www.alzheimers.org.uk

enquiries@alzheimers.org.uk Helpline: 0845 300 0336

The leading UK care and research charity for people with dementia and their carers. Produces an extensive range of fact sheets on all aspects of dementia, and runs a national network of support groups and other services 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)

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.

BRITISH RED CROSS 44 Moorfields London EC2Y 9AL 0870 170 7000 www.redcross.org.uk

Offers crisis respite sitting services, to enable people who care for someone with dementia to take a break.

CARERS UK

20-25 Glasshouse Yard London EC1A 4JT **020 7490 8818** www.carersuk.org Helpline: 0808 808 7777

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

CITIZEN'S ADVICE BUREAU

Myddleton House 115-123 Pentonville Rd London N1 9LZ 020 7833 2181 www.adviceguide.org.uk

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

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.

CROSSROADS CARE SCHEMES

10 Regent Place Rugby Warwickshire CV21 2PN www.crossroads.org.uk

01788 573653

Offers support for people with dementia in the home. Trained workers provide free home care.

DEPARTMENT OF HEALTH

Richmond House 79 Whitehall London SW1A 2NL 0207 210 4850 www.dh.gov.uk

UK Government department with responsibility for health.

FOR DEMENTIA

6 Camden High Street London NW1 0SH 020 7241 8555 Tel: 020 7874 7210 www.fordementia.org.uk

Promotes nursing care for people with dementia.

THE HUNTINGDON'S DISEASE ASSOCIATION 108 Battersea High St

London SW11 3HP TEL: 020 7223 7000 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.

USEFUL CONTACTS (CONTINUED)

THE MENTAL HEALTH FOUNDATION

Sea Containers House 20 Upper Ground London SE1 9QB 020 7803 1100 www.mentalhealth.org.uk 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.

NHS DIRECT Helpline: 0845 46 47

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

PARKINSONS'S DISEASE SOCIETY

215 Vauxhall Bridge Road London SW1V 1EJ 020 7963 9380 (chk) **Helpline: 0808 800 0303** www.parkinsons.org.uk

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

SOLICITORS FOR THE ELDERLY PO Box 257 Broxbourne Hertfordshire EN10 7YY 01992 471568 (9am-1pm Mon-Fri) 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.

THE STROKE ASSOCIATION

Information Service Stroke House 240 City Road London EC1V 2PR 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.

WINGED FELLOWSHIP TRUST

Angel House 20-30 Pentonville Road London N1 9XD 020 7833 2594 www.wft.org.uk

Provides information about supported holiday sites for people with disabilities.

SAMARITANS Helpline: 8457 90 90 90 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. A booklet about living with dementia

This booklet explains some of the **basic facts** about **dementia**, gives **ideas** on where you can get **practical** and **emotional** help, offers **advice** on planning for the **future**, and details some **strategies** which other people have used to **cope** with dementia.

Mental Health Foundation

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