

Older People's Mental Health and Memory Services

Useful information



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Introduction

This booklet aims to provide a short and straightforward guide to the questions that many carers have asked us in the past. The work in the department is at the forefront of care, with pioneering research and services.

We are committed as a team to provide good information to patients and carers, and we hope this booklet aids that process.

If you have any comments or questions that you would like to see added to this booklet then please contact:

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The Diagnosis

What is Dementia?

Dementia is a generic or 'umbrella' term for conditions that have an effect on both short and long-term memory. In addition to memory loss, a progressive loss of other mental abilities takes place which is often accompanied by changes in behaviour and skills. Common symptoms may include:

- Disorientation in time
- Difficulty in word finding
- Difficulty in understanding what people are saying
- Getting lost in familiar places
- Repetition in speech or behaviour

The symptoms described above are common in dementia, although they may not all be present at once. As dementia is a disease that affects the brain's function, a person who has dementia will often present in a different way to another person with the same diagnosis. Due to this fluctuation in the person's presentation, the role of the carer in this condition is very important. Carers are an invaluable source of information for the team, they enable us to gain an insight into any changes the patient may have experienced as a result of their condition.

Dementia is a progressive illness and has the effect of reducing the function of the brain, by destroying brain cells (neurons) which cannot be replaced. The most effective treatment available for some types of dementia at the moment acts to increase the function of neurons by boosting a chemical that exists in the brain naturally, but has been noted to be low in people diagnosed with dementia. Treatment may not be suitable or effective for all patients and the benefit of treatment may be time limited.

Dementia can be present in many different forms. These include:

- Alzheimer's disease
- Vascular dementia (also referred to as multi-infarct or arteriosclerotic)
- Dementia with Lewy Bodies, and Parkinson's disease dementia
- Fronto-Temporal dementia
- Early onset dementia
- Other, rarer types of dementia

What is Alzheimer's disease?

The most common type of dementia is Alzheimer's disease, and accounts for about 50-60% of all dementia diagnosed. People in the early stages of Alzheimer's disease commonly complain of memory impairment, impaired ability to grasp new ideas, decreased motivation, anxiety about everyday life and irritability when they find everyday tasks more difficult. As the disease

progresses, the deficits in the person's ability to function becomes more noticeable. The impairment in memory is more obvious and sufferers can become increasingly disorientated in time and space, getting lost and confusing day with night. Tasks that were previously simple may become difficult and confusing for them and it may become more difficult for them to hold a conversation as effectively as before. Other changes may include, agitation, mood and personality changes.

The direct cause of Alzheimer's disease has not yet been found. We know there are some possible risk factors, which include increasing age, head injury, genetics and Down's syndrome. Please note that these are only risk factors and it does not mean that you will develop Alzheimer's disease if some of these risk factors are relevant to you. If you have any concerns then please ask for further information or contact your GP.

What is Vascular Dementia?

This type of dementia can occur following a stroke or over time through a series of small strokes. The term stroke refers to the disruption of the blood supply to the brain tissue. Most strokes occur when a blood clot blocks a vessel carrying blood to the brain. When the blood supply is disrupted the brain cells are deprived of oxygen and other nutrients, causing some cells to become damaged and others to die. The type of problems that arise depends on where the stroke damage has happened, as different parts of the brain have different roles. This is because the stroke may not show in physical changes like weakness.

What is Dementia with Lewy Bodies?

Dementia with Lewy Bodies share similarities with Alzheimer's and Parkinson's Disease. As with Alzheimer's disease, dementia with Lewy Bodies is caused by degeneration of nerve cells in the brain. People may experience the same types of symptoms as someone with Alzheimer's disease but commonly suffer from visual hallucinations (a mistaken belief that they see something that isn't really there).

The patient may also fall for no reason. They may develop Parkinson-type symptoms such as slowness, and stiffness of movement. The symptoms may fluctuate from hour to hour and day to day.

What is Frontotemporal Dementia (FTD)?

This is another uncommon type of dementia and predominantly affects the frontal lobe part of the brain. The frontal lobe governs our voluntary movements, personality, concentration, organisation and problem solving abilities. Common symptoms of FTD include behaviour that is fixed and difficult to change making the person appear selfish and unfeeling. Changes in personality are often the most noticeable difference in someone with frontotemporal dementia, often involving higher incidences of impulsivity, mood disorder and stubbornness. There may be changes in speech and language.

What is Early Onset Dementia?

Describes when dementia is diagnosed in those under 65 years old. The causes of the dementia are the same as with older people but in different proportions. Alzheimer's disease is less common affecting one third (60% in older people with dementia) but fronto temporal dementia is more common. Other causes of dementia in younger people are Vascular Dementia, Dementia with Lewy Bodies, Alcohol related Dementia and the much rarer forms: Creutzfeldt-Jakob, Huntingtons, Parkinsons, HIV.

Summary

These are only some of the more commonly encountered types of dementia. There are other types of dementia and the descriptions above are very generalised. After hearing a diagnosis, patients and carers normally experience a range of emotions. We have found that many patients and carers feel that having access to more information about dementia helps them to come to terms with the diagnosis and enables them to start planning for the future.

A number of our partner organisations produce a range of detailed information books and factsheets. A list of contact details are on page 19 of this booklet.



SECTION 2

Ongoing care

If you have been referred to the Older People's Mental Health Service by your GP you will receive an initial assessment to decide what type of support you need. This could be provided through your GP, Adult Services, a local Community Mental Health Team or Memory Service. You will either be seen in your home, a local community setting or at an outpatient clinic in a local hospital. You will get regular reviews to ensure you are receiving the right level and type support for your needs.

SECTION 3

Research

Research trials are used to help with understanding how to diagnose, treat, cure or prevent disease. This may involve comparing existing treatments or looking at new ones. They are important to ensure that the best advice and treatments are being provided to patients.

The Older Peoples Mental Health Research Department, MARC, was established in the early 1990s. It has taken part in many important research trials which have lead to the currently available medications, e.g. Aricept. MARC is one of the leading centres in Europe for dementia research: Dr David Wilkinson and Professor Clive Holmes are internationally renowned for their expertise in this area. The MARC team is multidisciplinary, consisting of psychiatrists, psychologists, nurses and administrative staff.

New trials are constantly being run which may be of benefit to patients with dementia and carers. Those attending trials may get their travel expenses reimbursed or free transport arranged. To find out more please speak to your memory nurse or doctor or contact the department direct on **023 8047 5206**.

Website address: **www.southernhealth.nhs.uk**

SECTION 4

Managing finances and benefits

An important step following a diagnosis is considering how you will manage financial arrangements in the future. Undertaking a caring role for someone with dementia may mean that you are entitled to a number of benefits or the person you care for may be eligible for benefits.

Benefits

The Benefits and Social Security system can be perceived by many as being complex, time consuming, frustrating and generally not worth the hassle. Other views are that you are taking handouts from the state and people may feel uncomfortable accepting them.

Please remember many of these benefits are not means tested and have been set up to acknowledge your need for care.

If you have not already done so, we recommend that you at least review your current financial situation sooner rather than later. Here is a summary of the main avenues that you may wish to pursue. It is by no means a complete overview, and there will be further information and support available to you from staff supporting your needs (GP, Adult Services, Community Mental Health Team or Memory Service).

What other benefits are available ?

There are many benefits available for older people, such as:

- Help for people on a low income
- Retirement pensions and bereavement benefits
- Benefits for people with disabilities and their carers
- Financial assistance and reductions.

Here are a few benefits that we would already like you to consider applying for **NOW** if you have not done so already.

● Attendance Allowance

The person being cared for must be over 65 years (if not, apply for Disability Living Allowance). It is not means tested. It is provided for those who need help and supervision with daily life activities. The forms take about an hour to complete, but it is worth around £47-£70 per week. Contact Department of Work and Pensions for more help. For all government benefits go to **www.dwp.gov.uk** or telephone **08457 123456**.

- **Disability Living Allowance**

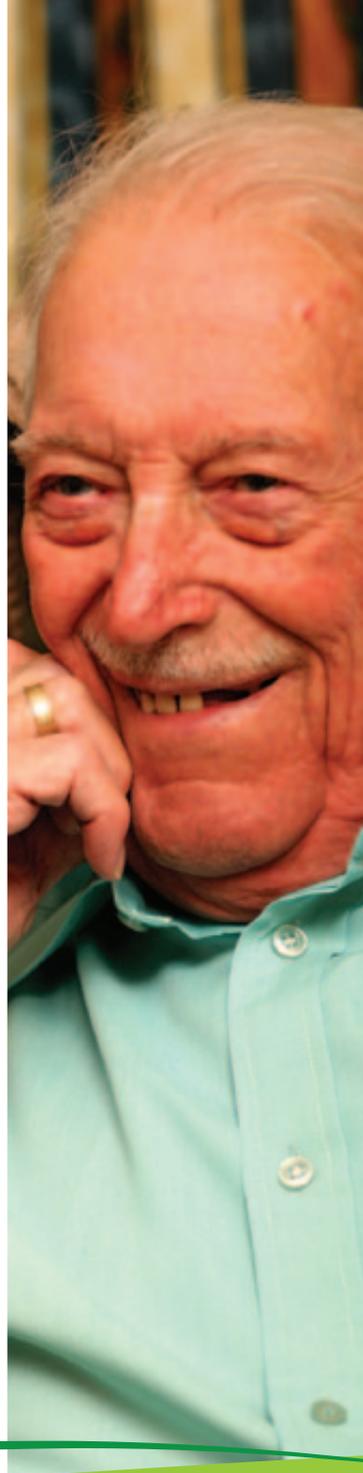
The person being cared for is under 65. The same rules apply as for Attendance Allowance.

- **Carers' Allowance**

Paid to carers' who look after someone for at least 35 hours per week. The person being cared for must be receiving Attendance Allowance or Disability Living Allowance for the carer to qualify. This benefit is taxable and is currently around £50.

- **Council Tax**

Households with a person with a diagnosis of Dementia may be entitled to a reduction in Council Tax contributions (25% if living with someone else, 100% if living alone). However this does not apply if there are more than two adults living at the property. Ask at your local council office for more information and how to apply as different local authorities have different processes for applying.



Looking after yourself as a carer

In many cases the carer may become responsible for helping maintain the daily functioning of the person with dementia. The level and degree varies with each person but there is something that is almost always forgotten, ***if you were not there, who would do the caring duties?***

Feelings

Being a carer can be overwhelming. There are a number of feelings commonly experienced by carers including guilt, exhaustion, embarrassment, helplessness and anger.

Looking after yourself

It's all too easy to ignore your own needs when caring for someone with dementia and forget that you matter too! Allow family and friends to be involved and try not to turn away help, these offers are usually genuine and can greatly help you and the person you care for. Do look after your own health (sleep, diet, exercise, etc). Ensure that you have time for yourself and do not feel guilty about this protected time.



Help with moving about

There are some general pieces of guidance to be passed on when considering moving and handling of someone who may have difficulty in walking or rising from a bed, chair or toilet. Keeping the person mobile will encourage them to do as many things for themselves as they can possibly manage. Cooperation is required. You may have to become more ingenious in your communication methods in order to persuade the person to remain active. It is important to highlight safety as a consideration and never attempt to lift someone on your own. There are aids and adaptations available to help in and around the home (chair risers, walking aids, etc). If you encounter problems, you can contact a Physiotherapist or Occupational Therapist via your GP or Community Mental Health Team for some practical help or advice.

Staying healthy

Both you and the person with dementia will want to remain as healthy as possible. The better you both feel, the more you enjoy life. Try to arrange annual general health checks with your GP. Try to take the advice about good mobility, diet, regular dental and eye checks, low alcohol intake, cut down on smoking, be aware of any hearing deficits and keep an eye on any foot problems. This list is not exhaustive and is as much applicable to the carer as to the person with dementia.

‘Memory Matters’ Carer Education course

Southern Health NHS Foundation Trust offers an eight week carers education course that runs several times a year, for carers who want to find out more about dementia. There are memory matters courses running in a number of locations across Hampshire. Please ask a member of the team for more information

People with dementia whose carers are attending Memory Matters can attend a group aimed at giving them information and support. This group runs at the same time and place as the carer’s group.

The course covers such subjects as:

- What is Dementia?
- What treatment is available?
- What services are available to support someone with dementia and their carer?
- Activities and communication
- Explore ways of coping (including Managing Challenging Behaviour)
- Looking after yourself as a carer
- Making the most of memory
- Financial support available
- Legal issues and financial support available to carers.

The course is structured so that carers participating can request other topics (in addition to the above) be included in the course. It offers the opportunity for carers to share their feelings and find out how to get support from other carers. There is no charge to attend this course.

For details of your local course contact:

Your local Community Mental Health Team

Legal Arrangements and Financial Issues

It is important to plan ahead and there are other important financial and legal considerations you may need to consider such as:

- Legal issues concerned with managing the financial affairs of the person with dementia
- Making your Will
- Dealing with someone's estate

Your Community Mental Health Team or Memory Service has information on the issues above and to help you understand some of the terminology. Here is a quick overview of some of the common arrangements usually made. If you consider applying for them, then we would advise you to seek advice from an appropriate person such as a solicitor.



- **Mental Capacity**

This is basically the ability to understand and retain information adequately, enabling competent decisions to be made. It must be remembered that the law assumes all adults 'are competent' in communicating and making decisions. The problem with dementia is that the decision-making processes may fluctuate or be impaired.

- **Agency**

A person who receives a benefit or a pension may nominate someone – called an 'agent' – to collect the money for them, but not to spend it.

- **Appointee**

If someone who is entitled to a Social Security benefit or allowance is unable to act for themselves (because of dementia) a representative of the Secretary of State for Social Security – usually the benefit supervisor in the local Benefits Agency (Social Security office) – may, on receiving the application, appoint someone else to exercise the claimant's right to make claims for and to receive benefits, and to spend them on behalf of the claimant. It is accepted policy that a close relative who lives with or frequently visits the

claimant is often the most suitable person to act. There are guidelines and powers demanded of an appointee.

- **Third Party Mandate**

This can be used by someone who is mentally capable but is unable to carry out a particular transaction – for example, the person may be physically unable to visit the bank, and may need someone to do this on their behalf.

- **Lasting Power of Attorney (LPA)**

From 1 October 2007 the new Mental Capacity Act came into law and as part of this Lasting Power of Attorney replaces Enduring Power of Attorney (EPofA). However, any EPofA made out (registered or unregistered) before that date still stands.

The new LPA extends not only to legal and financial affairs but also to some aspects of health care and welfare decisions. This new part of the Mental Capacity Act enables individuals who still have capacity (that is the ability to make decisions) to set out their wishes to refuse medical treatment in the future should they lose capacity. This is also known as an 'Advance Decision'.

You can find out more information from the Public Guardians' Office at **www.publicguardian.gov.uk**. Follow the links to Lasting Power of Attorney or Mental Capacity Act. Solicitors can offer expert advice on setting up a LPA and Advance Decisions, and advise of the cost of arranging these. You can do the paperwork yourself if you feel you are capable.

● The Court of Protection

The Court of Protection is an Office of the Supreme Court. It exists to protect the property and financial affairs of people who are by reason of a mental disorder incapable of dealing with their own affairs. The Office is also responsible for the registration of Enduring and Lasting Power of Attorneys and for giving directions where the Court has decided that a Receivership Order is unnecessary. Applications to manage someone's legal and financial affairs when they lose the ability to do so and no Lasting or Enduring Power of Attorney is in place are made to the Court of Protection who will then appoint someone to act as an attorney.

Important Note

We would advise carers to seek appropriate advice, eg. from a solicitor, in dealing with the above financial matters.

Further information

A number of useful and up to date information resources are available and we would be happy to give these to you. Please visit our website **www.southernhealth.nhs.uk** or speak to a member of the team.

Useful numbers:

- **NHS Direct**

Tel: **0845 46 47** www.nhsdirect.nhs.uk

- **Alzheimers Society**

Tel: **020 7423 3500** www.alzheimers.org.uk

- **MIND**

Tel: **0845 766 0163** www.mind.org.uk

- **The Princess Royal Trust for Carers in Hampshire**

Tel: **0845 604 1577** www.carers.org.uk

- **Carers Together**

Tel: **01794 519495** www.carerstogether.org.uk

- **Age UK** (*previously Age Concern AND Help the Aged*)

Tel: **0800 169 6565** www.ageuk.org.uk

- **The Stroke Association**

Helpline: **0303 3033 100** www.stroke.org.uk

- **Hampshire Advocacy Regional Group**

Tel: **023 8071 5679** www.hampshireadvocacy.org.uk

- **Department of Work and Pensions (DWP)**

Tel: **08457 123456** www.dwp.gov.uk

- **Hampshire Adult Services**

Tel: **0845 603 5630** www.hants.gov.uk

- **Southampton Adult Services**

Tel: **023 8083 3003** www.southampton.gov.uk

Contact us

● Contact: _____

Tel: _____

Address: _____

Patient Advice and Liaison Service (PALS) and Complaints

PALS and Complaints can provide you with support, information and advice that is totally confidential and impartial.

Contact them on: Tel: **023 8087 4065** Fax: **023 8087 4178**

or email: **hp-tr.complaints@nhs.net**

or write to: FREEPOST RSJL- JXSX-ATUE,

PALS and Complaints Department, 5-6 Sterne Road,
Tatchbury Mount, Calmore, Southampton SO40 2RZ

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please contact the Communications Team

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