Forgetting where the car keys are, or what’s-his-name’s name makes us joke about Dementia. But, it’s no laughing matter when someone is diagnosed with it. This is our introduction to Dementia and Alzheimer’s which we hope you find useful. It is a really frightening thought that someone you love might have Dementia – but there are ways to live well with Dementia, and many resources available to support you and them. There is more information at www.agespace.org including our forum to ask questions or share your experience.

What is Dementia, and what is Alzheimer’s?

The word dementia describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. These changes are often small to start with, but for someone with dementia they become severe enough to affect daily life. A person with dementia may also experience changes in their mood or behaviour.

Dementia is caused when the brain is damaged by diseases, such as Alzheimer’s disease or a series of strokes. Alzheimer’s disease is the most common cause of dementia but not all dementia is due to Alzheimer’s. The specific symptoms that someone with dementia experiences will depend on the parts of the brain that are damaged and the disease that is causing the dementia.

Getting a diagnosis early can help in some cases where there are drugs that can delay the progression of the disease.

Types of Dementia

There are 4 types of Dementia, two of which are the most common – Alzheimer’s and Vascular Dementia.

Alzheimer’s accounts for about two-thirds of cases. It is not always obvious to begin with and symptoms can be subtle and overlap with other illnesses such as depression. In the early stages, it can sometimes be difficult to distinguish Alzheimer’s from mild forgetfulness.

Vascular dementia symptoms can include memory loss, disorientation and problems with communication. More specific symptoms may differ depending on the area of the brain that is affected. Symptoms include - thinking skills – taking more time to process information and problems with attention, planning and reasoning. Personality changes – these may include depression and apathy. People may also become more emotional. Movement problems – difficulty walking or changes in the way a person walks. Bladder problems.

Dementia with Lewy’s bodies (DLB) symptoms including memory loss, spatial awareness problems and a decline in problem-solving skills. There are also some more specific symptoms associated with the disease. Some of which are also seen in Parkinson’s dementia which include movement and motor problems.

Frontotemporal dementia or FTD (Pick’s disease) is a relatively rare form: early symptoms vary but may include changes in behaviour, understanding of language and factual knowledge and/or the ability to control speech.
Diagnosis and Treatment

Tests for diagnosing dementia

There are memory and other brain tests that can be carried out by the GP and because dementia gets worse over time, the tests may be repeated, perhaps after six to 12 months, to see if there have been any changes.

Other tests, including blood tests and brain scans, could be arranged. Very occasionally, the doctor may arrange an EEG (brain wave test) or a lumbar puncture (spinal tap) if they suspect a rare form of dementia. In a lumbar puncture, a needle is used to take a sample of fluid from the bottom of someone’s spine.

Treatments

There is no cure currently, but there are drugs that can help slow down the progress of Dementia, and alleviate symptoms.

The 2 main types of drugs to treat Alzheimer’s are - Cholinesterase inhibitors (generic versions called donepezil, rivastigmine or galantamine) and/or NMDA receptor antagonists.

Living well with Dementia

Following a diagnosis the first step is to get a health and social care needs assessment. This is how a person with dementia, and the person or people looking after them, gets help and support from their local authority’s social services department.

The assessment will find out what help and support needed – such as healthcare, equipment, care services at home, or a stay in a care home. If a person with dementia has ongoing medical care needs, they may qualify for free NHS continuing care, which will be assessed by the NHS.

It is possible for many people with dementia stay in their own home with good support, either from family carers, community nurses or paid care workers. Being in familiar surroundings can help people cope better with their dementia.

For more support at home, Admiral Nurses, provided by Dementia UK, work in the community providing individual support. Marie Curie also provide Dementia trained nurses to give support at the end of life at home, or in their hospices.

Other Treatments

Anti-depressants may be prescribed as depression is quite common amongst people with Dementia.

There are also different therapies that might help with behaviour changes, such as CBT (cognitive behavioural therapy). These may alleviate symptoms, but won’t alter the overall decline.

For further information on treatments, download The Alzheimer’s Society factsheet.
Living well with Dementia

Keeping people with dementia active and meeting others can have very positive effects in the management of their condition. One great way to meet others is via local dementia “memory cafes”. These drop-in centres allow people with dementia and their carers to find advice and support from others who share the experience. Check out Dementia Connect for information about the cafes and other local activities.

If you want to do something more active like going for days out and perhaps even take a short break but worried about managing the person with dementia’s needs there are organisations to help.

Dementia Adventure offers outings and short breaks, such as barge sailing and woodland walks, designed for people living with dementia and their carers to enjoy together.

Online forums are a great way to share your experiences of caring for someone with dementia, as well as reading what others are going through. If there’s something you are struggling with, the chances are that someone else has had the same experience.

Talking Point is the Alzheimer’s Society’s forum. It has people with dementia sharing their information and advice, and supporting each other. Carers can also turn to online communities on the Carers UK forum and the Carers Trust forum.

If you are looking after someone with dementia or worried about a parent who is the carer, it’s important that you know how to get help and support for you/them as well. The Dementia Carer is a good place to start looking for information and advice on how to get help and support, and even a break from caring.

Practical considerations

Power of Attorney

No-one wants to lose the ability to make decisions about their health, care or finances, but unfortunately this may become a reality for someone living with dementia. Establishing a Power of Attorney before this day comes enables control over decisions when someone is no longer able to make them.

An Ordinary Power of Attorney is valid while someone has the mental capacity to make their own decisions about their finances. The power given can be limited to dealing with certain assets, for example, a bank account, but not their home. It may be useful if your parent is going into hospital and they want someone to deal with their bank account while there. It does not need to be registered before being used.

A Lasting Power of Attorney (LPA) continues to be valid if your parent loses their mental capacity and is no longer able to make their own decisions.

There are two types of LPA: Property and Financial Affairs LPA to cover decisions including: selling a home, paying the mortgage, investing money paying bills and arranging repairs to the property.

Personal Welfare LPA covers healthcare and personal welfare and covers decisions including: medical care, where to live, how they live, who they see.

A LPA is only valid if your parents have the mental capacity to set it up and haven’t been put under any pressure to create it. The LPA must be signed by a certificate provider, someone they know such as a doctor, social worker or solicitor and it can only be used once it is registered with the Office of the Public Guardian.

A third-party mandate

This document enables a named person other than the account holder to give instructions to the bank, building society or other account provider. It gives that person the authority to run the account. There are usually some restrictions on what they can do, such as not being allowed to arrange a formal overdraft or open or close an account for the account holder.
Organisations that can help

Age UK
Their website has useful resources on health and wellbeing, care at home, funding care, and products to help you live safer and more comfortably at home. Age UK is made-up of local Age UK chapters that can help and the chances are you will find one close to where you or your loved one lives.
Website: [http://www.ageuk.org.uk/](http://www.ageuk.org.uk/)
Call: 0800 169 2081 for advice or information.

Independent Age
Independent Age is a charity offering free advice and information on care. Their Wise Guides particularly useful and you can order them for free. The Guides cover a range of areas, such as Your Health and the NHS.
Website: [http://www.independentage.org/](http://www.independentage.org/)
Call: Advice line on 0800 319 6789

Society of Later Life Advisers (SOLLA)
SOLLA is a not for profit organisation that helps families to find specialist local advisers, accredited by SOLLA. They provide invaluable advice on issues affecting older people, including long-term care, savings, pensions and equity release.
Website: [www.societyoflaterlifeadvisers.co.uk](http://www.societyoflaterlifeadvisers.co.uk)
Call: 0845 303 2909

Which?
Which? Elderly Care helps families to understand their care choices. Their site helps visitors to understand their relative’s needs, housing options and paying for care. They have a really useful Care Advice Tool for people who aren’t sure where to begin.
Website: [www.which.co.uk/elderly-care](http://www.which.co.uk/elderly-care)

Unforgettable.Org
Unforgettable is a new organization, founded with the support of the Alzheimer’s Society. It provides specialised products and practical advice for people affected by dementia. Their newsletters, blogs and forums are easy to follow and they have a simple marketplace for families to find dementia products. These products help with everything from safety at home, to mobility aids and personal hygiene.
Website: [https://www.unforgettable.org](https://www.unforgettable.org)
Call: 0203 322 9070

Alzheimer’s Society
The Alzheimer’s Society is the leading care and research charity for people with Alzheimer’s and dementia. Their comprehensive website is full of useful advice and guidance on the disease, including what it is, symptoms and diagnosis, how to live with it and how to care for someone with the disease.
Website: [www.alzheimers.org.uk/](http://www.alzheimers.org.uk/)
Call: 0207 423 3500

Good Care Guide
The website provides an independent forum to allow people to find rate and review elderly care options across Britain. People share views on the quality of care, staff, facilities and value for money.
Website: [www.goodcareguide.co.uk](http://www.goodcareguide.co.uk)

Care Quality Commission
The Care Quality Commission is the independent regulator of all health and social care services in England. They monitor and inspect services to make sure they meet quality and safety standards. They publish what they find, including performance ratings to help people choose care.
Website: [www.cqc.org.uk/](http://www.cqc.org.uk/)
Call: 03000 616161

Carers UK
Carers UK are the UK’s national membership charity for family carers. The charity provides advice and support to carers, with expertise on benefits, tax credits and employment rights.
Website: [www.carersuk.org/](http://www.carersuk.org/)
Call: 0808 808 7777

There is more information on our website [www.agespace.org](http://www.agespace.org) on a much wider range of subjects.
You can also join our forum and get involved in the conversation.