

LIVING WITH DEMENTIA Information & Resource Guide



Introduction

People may have heard of the word or loosely used the word “dementia”, but they don’t always have a clear idea of what “dementia” is.

It is often said that the only constant in life is change. As we grow, our health, our bodies, our ways of thinking, behaviours and habits change. We all experience the effects of normal aging. These include mild forgetfulness and the slowing down of reflexes.

However, there is disease known as ‘dementias’. In the early stages, the signs and symptoms look like age-related changes but they are not. It is therefore helpful to be aware of what changes are considered part of a disease process.

What is Dementia?

When we are born, the brain contains billions of nerve cells. Unlike other cells of our body, Nerve cells (called neurons) **DO NOT** reproduce themselves.

This means that as we age, the neurons that die from wear and tear and also from injury, do not replace themselves.

Dementia is a term used to describe a collection of diseases that damage our neurons. With dementia, more and more damage to our nerve cells occurs. We see this damage more easily in how it affects our behaviour and our thinking abilities. Observable changes take place in one or several areas of thinking and behaving.

Below you will find some areas that you or your family and friends may recognise as having changed for the worse, over a number of months.

- **Memory** (consider difficulties recalling new day-today information, difficulties remembering past and general knowledge and also personal information);
- **Language** (consider word-finding difficulties, changes in spelling and reading abilities, problems expressing yourself or difficulties understanding what has been said to you);
- **Viso-spatial skills** (an example of this is changes in your ability to dress yourself; a reduction in practical abilities like “Do-It-Yourself” work; getting lost in familiar surroundings; unable to recognise familiar landmarks);
- **Thinking and problem solving abilities** (making poor judgements; difficulties solving everyday problems, thinking about the future, difficulties planning or organising yourself or even your day);
- **Numerical skills** (negative changes in your usual ability in dealing with money, such as difficulties in doing the shopping, not able to manage household accounts);
- **Visual perception** (this means having problems recognising and identifying people who are usually familiar or well-known to you)
- **Changes in your personality** (noticing that you are behaving ‘out of character’ or being told by family and friends that you are ‘behaving’ out of character’).

What Are The Common Types Of Dementia?

There are several types of dementia.

1. **Alzheimer’s disease:** This is the most common type of dementia affecting more than 50% of all of those with a dementia. Damage to nerve cells and nerve pathways are caused by proteins, which form ‘tangles’ or ‘plaques’ in the brain
2. **Vascular Dementia:** This is also quite common. It affects about 20% of people. It is caused by poor blood circulation in the brain. The blood flow to the brain cells is interrupted, it does not receive the necessary oxygen and nutrients. Consequently, brain cells die.

3. **Mixed Dementia:** It has been found in research and in clinical practice, that people can be affected by **both** Alzheimer's disease and vascular dementia.
4. **Dementia with Lewy Bodies:** This dementia affects about 15% of people with dementia. The development of small protein bodies called Lewy Bodies damage the brain cells.
5. **Fronto-Temporal Dementia:** Only about 5% of the dementia fall into this category. It tends to affect people of a slightly younger age. Damage is caused to the frontal and temporal lobes. Pick's disease is one type of fronto-temporal dementia

Progression of Dementia

Dementia becomes progressively worse over time. The key point to remember is this:

Everybody will experience dementia in his or her own unique way.

The way we experience dementia will depend on a number of different factors, including our physical make-up, our personality style, our emotional resilience and the support received.

It is important to bear in mind that signs and symptoms appear and disappear throughout the disease process. Sometimes they overlap with one another.

Some symptoms may appear more pronounced on one month and not in another.

Acknowledging and accepting that the disease process DOES NOT run an exact predictable course can be a helpful perspective to adopt. Promoting and retaining independence for as long as possible is valuable. Over time, as skills and abilities diminish, support and input need to increase.

For further information contact the Alzheimer's Society who can provide you with more details.

Helpful Strategies

You can use these strategies independently or together with your loved ones or close friends.

Consider putting these strategies in place to assist you. Make it part of your routine to make life easier.

Tips for doing things:

1. Carry a notebook or diary – write things down and tick it when tasks are completed. Refer to your notebook/diary several times a day.
2. Use a Dictaphone in the same way – to record things to do. Record when they are completed. Refer to it several times a day.
3. In the home, use a memo-board, a dry-wipe board or "post-it " sticky notes. Cross off all completed tasks.
4. Keep a structured routine for taking tablets. Electronic pillboxes have a beeper to alert you when it is time to take your tablets
5. A pager, an alarm clock or an electronic organiser can help remind you of things to be done.

Tips for going places:

1. Always try to use the same route. Be very aware of your surroundings. Looking for landmarks like churches, pubs, schools, a garage, and a shopping centre can be very helpful.
2. If you are going somewhere unfamiliar, take a telephone number of a close friend or relative with you. Write down directions or ask someone to write down the directions for you. Use a Dictaphone as alternative way to record details.

3. Always keep in your wallet, your name, address and a contact telephone number of a close friend or family member. In the event of an emergency, passers-by will be able to contact your loved ones.
4. You can also buy iron-on labels (with your name and address) to put on your clothing.

Where is it?

1. 'A place for everything and everything in its place'. Always put things back in their place.
2. Stick labels and/or picture on cupboards, drawers, doors, etc., telling you what items may be found there.
3. Use see-through containers for small items
4. Attach a string to keys and tie it to your belt hook. Attach a chain or cord to your glasses to wear around your neck.
5. Write all important phone numbers in large print and keep them near the phone or stick them on the wall above the phone. Ensure you have important phone numbers in your diary or notebook as well.
6. When going out, always try to carry all-important items in a single bag.

Some people who have a diagnosis of dementia will be eligible for treatment with drug treatments. Not all people gain benefits from the treatment and they are not indicated for all types of dementia. Please talk with your health care professional regarding your suitability to receive treatment,

Legal and Financial

You will need to ensure that your finances are in order to make things easier for you to manage. If necessary ask a member of the family or a trusted friend to give you a hand. It will be easier if you keep things in order; setting up direct debits for bills is a good idea and ensures that the bills are paid without you having to remember to pay them at regular intervals. Use a notebook to jot down how and when bills are paid and groceries are bought as this will help you to keep track of things.

Money received from pensions, benefits and investments can be paid directly into your bank account.

Your own preferences for care and treatment are important; your care team will support your choices wherever possible. However, as your needs change you may not be able to make some decisions or communicate your needs. There is now legislation to protect you, this provides a framework that healthcare professionals will follow. The Mental Capacity Act 2005 (www.dh.gov.uk) ensures that your interests are protected and gives specific guidance that will enable your capacity to be assessed.

Benefits:

To qualify for any benefit the person with dementia or their carer will need to meet certain conditions. These vary depending on the type of benefit and some are means tested. As a minimum, Attendance Allowance or Disability Living Allowance can usually be claimed by the person with dementia. Your care manager, social worker or local Citizens Advice Bureau will be able to advise you of your entitlement or you can contact one of the organisations listed below:

- Department of Work and pensions www.dwp.gov.uk
- The Pension Service www.thepensionsservice.gov.uk
- The Benefits Enquiry line 0800 88 22 00

Lasting Power of Attorney:

- The Mental Capacity Act 2005 makes provision for you to appoint a person of your choice to manage your finances, property and make future health and welfare decisions on your behalf. It is also advisable that you make a Will. You will need to speak to a solicitor of your choice regarding these matters.

What is an advance directive or “Living Will”?

An advance directive indicates:

- Your specific wish to refuse all or some forms of medical treatment and the circumstances under which this refusal would apply.

It must be prepared when you are mentally capable and is only used once you have lost the capacity to participate in the decision making process. Advanced directives are recognised and must be upheld under common law. For more information contact the Alzheimer’s Society/national dementia helpline

www.alzheimers.org.uk/

Driving & Dementia

Driving safely is a practical and legal requirement of all road users. People with a diagnosis of dementia should consider following legal responsibilities.

Legal Requirements

- By law, you must inform both your insurance company and the DVLA of your diagnosis of dementia.
- It is a criminal offence to withhold this information from the DVLA and you can be fined up to £1,000.
- By law, people with dementia must be regularly reviewed to assess their ability to drive safely.

Anyone who poses an unacceptably high risk on the roads should stop driving. This includes people with dementia.

For further information, contact the drivers medical section at the DVLA on 0300 790 6806.

For people who wish to continue driving, they should request a medical investigation. Following this, if the DVLA requests driving assessment, with your permission, they will contact your GP or psychiatrist. The DVLA will cover the cost of the driving assessment, if they request it.

The Driving Assessment and Advice Centre has been accredited by the Department of Transport. They can arrange an independent on-and off-road driving assessment. It costs £95.00. Advice on other aspects related to driving safely can be obtained. Contact tel number – 01622 795 719 for people living in the Kent area.

Notification of the diagnosis of dementia or mild cognitive disorder should be sent with the person’s driver number or full name and date of birth to:

**DRIVERS MEDICAL GROUP
DVLA
SWANSEA
SA99 1TU**

Tips for Driving Safely

1. Keep to familiar routes.
2. Use landmarks to help orientate yourself
3. Tell your loved ones how long you are likely to be out and what time you are expected back.
4. Discuss with loved ones which route you plan to use
5. Keep the address and contact details of the person or place you are going to.
6. If you are lost, stop and ask for help.
7. If you know how to use one, keep a mobile phone with you at all times.
8. Avoid busy areas.
9. Drive during daylight and in good weather.
10. Keep journeys short.
11. Use public transport for longer journeys.
12. Drive with a companion.
13. Avoid driving when distressed.

Alternatives to Driving

1. Use a local taxi service. Create an account. Find the details in your local directory or yellow pages.
2. Consider public transport. Travel Line is a national service, which provides travel information for any area. It offers timetables and fares for all types of public transport. Tel no: 0870 608 2608 (24 Hours).
3. Use a Volunteer Driver to take you places. There is a mileage charge. Ask for current rate. Volunteer Bureau Service: Tel no. 01322- 66 92 92 (Swanley) and Dartford: 01322- 27 24 76 or 01322- 29 11 64.
4. Contact the local Borough Council Transport Schemes to find out about concessionary fares within the local areas.
5. If you have mobility problems you can obtain a Blue badge from the Kent County Council, which will allow you to park in disabled parking bays.
6. For further information on dementia and driving, contact the Alzheimer's Society in your local area.

Risk Management

We can sometimes be faced with situations, which pose an unacceptable level of risk to loved ones or your own health and safety. These risks include the threat of self-harm or suicide and/or violence towards others (family or the public).

It is always helpful to have an updated list of important and useful telephone numbers at hand in the event of a crisis. Sometimes it can be very difficult to know how to identify and manage risks, it is important that you report any unmanaged risks to your health care professional and or Care Manager who will be able to discuss risk management with you.

Contact details for family members, neighbours, the GP, the A&E department of the local hospital, the police, the ambulance, your care manager, consultant, care-co-ordinator and pharmacy are useful to have pasted in a clearly visible and easily accessible place.

Advanced Care Planning

An advanced care plan supports people who want to decide in advance what kind of future and end of life care they would like when they become more unwell and less able to care for themselves. It is a statement of wishes and preference that are personal to you and can be about anything to do with future care. It is kept and shared with those who are involved with your care, including friends and family. It can cover any priorities for example:

- How you may want religious or spiritual beliefs' reflected in your care.
- The name(S) for people that you want to act on your behalf at a later time

- The choice of where you would like to be cared for
- Concerns solutions about practical issues i.e. who will look after the pets
- Your thoughts on different treatments and the types of care you may want to be offered
- Preferences regarding paramedics undertaking resuscitation if you were found collapsed.

An advanced care plan is not legally binding but if you lose the capacity to make decisions for yourself your previously expressed wishes will be taken into account by those acting in your best interests.

Lasting Powers of Attorney

A Lasting Power of Attorney lets you appoint someone to make decisions on your behalf. It's normally used when someone is unable to make their own decisions; there are 2 types:

- health and welfare
- property and financial affairs

You can choose to make one type of lasting Power of Attorney or both.

Property and Affairs LPA

You can make a property and affairs LPA to enable someone you trust (the attorney) to make decisions on your behalf about your property and affairs at a time when you are no longer able or lack the mental capacity to take those decisions yourself. This can include paying your bills, collecting your income and benefits or selling your house, subject to any restrictions or conditions you might have included. It can only be used once it has been registered at the Office of the Public Guardian (OPG).

Personal welfare LPA: A personal welfare LPA allows the person/s you have chosen as your attorney to make decisions on your behalf about your personal welfare, e.g. where you live. It can include the power of attorney to give or refuse consent to medical treatment if this power has been expressly given in the LPA. You have to fill in the form appropriately if this is the option that you require. If you do state that you do not wish to consent to specified life sustaining treatment to be given at a future time, the LPA giving the attorney the decision making power will invalidate a previous advanced decision refusing treatment, thus giving the attorney power to make the decision. A subsequent advanced decision (if applicable in the circumstances) would be binding on the attorney.

A personal welfare LPA can only be used once the form is registered at the OPG and you have become mentally incapable of making decision about your own welfare.

Who can make an LPA?

Anyone aged 18 or over with the capacity to do so.

What does having capacity mean?

To have mental capacity means being able to make your own decisions. We all make decisions, big and small everyday of our lives and most of us are able to make decisions for ourselves, although we may seek information, advice or support for the more serious or complex ones.

The law says someone lacking capacity cannot do one or more of the following four things:

- Understand information given to them
- Retain that information long enough to be able to make a decision
- Weigh up the information available to make a decision
- Communicate their decision

For large numbers of people their capacity to make certain decisions about their life is affected either on a temporary or on a permanent basis. The Mental Capacity Act (2005) covers situations where someone is unable to make a decision because the way their mind or brain works is affected, for instance, by illness or disability, or the effects of drugs or alcohol

Resource Directory

In addition to other resources listed there are various local services that can provide advice and practical assistance.

Kent Social Services:

- Provide a wide range of services and will provide you of other local services that maybe of help, anyone can make a referral on your behalf. Once a referral has been made a Care Manager will contact you or your family to arrange an appointment to come and see you at home and assess your needs. Some of the services they can provide include: day care, meals on wheels, assistance with personal care needs, advice regarding benefits, respite care and occupational therapy.

Telephone: County Duty 03000 41 61 61 Out of Hours: 03000 41 91 91

Age UK

- Can offer a wide variety of services including advice on benefits and staying healthy. There are several local Age Concern centres that provide services including day centres, help with bathing, legal advice and general support.

Telephone:

0208 765 7200 (Main Branch)

01322 226496 (Dartford)

01474 564 898 (Northfleet/Gravesend) 01322 385135 (Swanscombe)

www.ageconcern.org.uk

Dementia Web: Dementia information & resources for Kent & Medway

Email: info@dementiawebkentandmedway.org.uk

Alzheimer's Society:

- The society has expertise in information and education for carers and professionals. It provides help-lines and support for carers: National Dementia Helpline 0300 222 1122
The website also has a lot of useful information that can be accessed in the form of fact sheets. www.alzheimers.org.uk

Alzheimer's & Dementia Support Services (ADSS)

Information/Helpline: 0845 6044391/01474 5339900

Basement Flat

Dene Holm House

Dene Holm Road

Northfleet

DA11 9JY

Provide – Day care, support at home, practical advice and information, domiciliary care, befriending service, carers only support group. Free dementia cafes which run in the Dartford, Gravesham & Swanley localities during the month. Call 01474 5339900 for more information.

Patient's Advice and Liaison Service (PALS)

- **PALS** will offer you advice and support if you have any concerns about the treatment you are getting from your local National Health Service and can offer other information. **Telephone 0800 587 6757**

Care Navigator Service

- **Care Navigator Services** offer face-to-face confidential meetings to discuss your needs and guide you through a variety of options available in your local area. They can also offer information advice and guidance over the phone signposting you to local services. They offer a variety of services: Benefit awareness, information on care support services, Home maintenance, Safety in the Home, Assess and supply equipment and minor adaptations to the home. **Telephone 01322 294524 or 07808242517 (Gravesham) or 07702501703 (Dartford).**

Email: carenavigator@vawk.org.uk
www.vawk.org.uk

Carers First

- **Carers First** in Kent & Medway support Carers in North West Kent (Dartford, Gravesham, and Swanley) and South West Kent and offers a wide range of services from doctors visits, medicines, washing dressing, emotional support, etc. **Telephone 0300 303 1555.**

Crossroads

- Crossroads service aims to improve the lives of carers. They provide personal support, usually in the home environment to enable carers to have time to themselves and a break from their caring responsibilities. **Telephone 01322 336086**

Citizens Advice Bureau

- Assists people to resolve their legal, money and other problems providing free information and advice.
Telephone 01322 472 979 (Dartford) from May 2013
01474 361 239 (Gravesham)
01322 664 949 (Swanley)

www.graveshamcab.org.uk

24 Hour Kent & Medway Dementia Helpline: 0845 6044391

Information and emotional support for people with dementia and their carers

Independent Dementia Advocacy Service: Invicta Advocacy 01322 285 234

Supporting people with dementia who may have difficulty in representing their own interests. Supporting them to put forward their views enabling them to speak out.

The Silver Line – helpline for older people 0800 4 70 80 90

- No question too big, no problem too small, no need to be alone. They offer free, confidential and open 24 hours help line **Telephone 0800 470 80 90**

www.thesilverline.org.uk

MY PERSONAL DETAILS

NAME: _____

Phone No: _____

GP: _____

GP's Tel No: _____

Consultant: _____

Consultant' Tel No: _____

District Nurse: _____

Care Manager: _____

Care Co-ordinator: _____

Medication: _____

Pharmacy: _____

Darent Valley Hospital _____

Fire Brigade _____

Ambulance _____

Police _____