



SOUTHEND

MEMORY INFORMATION PACK

SECTIONS 1-4

January 2015

Contents



Section 1: Introduction

Section 2: Memory Problems and Dementia

Section 3: Living Well with Dementia

Section 4: Assessment, Support and Advice Services

This pack can be provided in alternative formats such as Braille, audio or large print.

Translations of this pack in alternative languages are also available.

For a copy of this pack in another format, please call: 01702 212500

or email: dementiasupport@southend.gov.uk

Section 1

Introduction

This booklet is an introduction and guide to the care, support and advice services in Southend-on-Sea for people affected by memory problems or dementia, this also includes their families and friends (in this pack collectively referred to as carers). It has been written for:

- those worried about their worsening memory problems, and their carers
- those with a diagnosis of dementia, and their carers

We understand that you may not wish to read the information in this booklet at this moment in time, but we hope you can refer to it as needed.

This booklet has been designed as a compact 'starter pack'. It is aimed particularly at those who have recently become aware of their own or a relative's memory problems, including those who have not yet sought medical advice or had a diagnosis. It explains how memory problems can develop and where to go for assessment and advice. It also explains what dementia is and how it affects people, and describes the assessment, treatment, advice and support services that are available in the area.

Just as everyone is different, so are individual preferences and needs. Obtaining individualised advice is very important. As with any medical problem, the first point of call should be the general practitioner (GP). This booklet also gives the contact details of many organisations in Southend that provide advice and support to people with memory problems.

To keep the booklet short and compact, it provides signposts to sources of information and advice about services locally. This booklet also gives the contact details of many organisations in Southend that provide advice and support to those affected by memory problems.

There are suggestions in the pack for how you might develop a diary or weekly planner to help keep a check on your appointments, and ways for staying healthy through diet and exercise.

The section 2 describes what dementia is and its symptoms. Section 3 summarises the most frequently offered suggestions about how to live well with dementia. Section 4 is an overview of the assessment, support and advice services in Southend, and focuses on the role of the National Health Service (NHS) memory services and the pathways into them. Section 5 is a directory of advice and support services in Southend that have expertise in dementia.

The National Dementia Strategy

The 2009 *National Dementia Strategy* seeks to transform dementia services, to raise the awareness of dementia, and to achieve earlier diagnosis and higher quality treatment at every stage of the illness.

The local dementia strategy for Essex, Southend and Thurrock outlines the way health and social services are working together to improve the lives of people affected by dementia across Essex. If you would like a copy of the Southend-on-Sea Dementia Implementation Plan or the local strategy please contact Southend-on-Sea Borough Council by email at dementiasupport@southend.gov.uk

Section 2

Memory Problems And Dementia

It is more common for a person's memory to be affected by age, stress, tiredness, certain medical conditions and some medications. This can be annoying if it happens occasionally, but if it affects your daily life or is getting worse, make an appointment with your GP to get their advice. Nevertheless, dementia is not a normal part of aging.

Dementia is not a single illness but a term for various symptoms of several conditions that can affect the brain. It can happen to anyone and there is currently no cure, but some treatments may slow the progression of the disease. The symptoms depend on the particular form of dementia but include:

memory loss, such as difficulties finding the right word, remembering where you have put something, and remembering past events more readily than recent ones.

problems thinking or reasoning, such as increasing difficulties with tasks and activities that require concentration and planning, or finding it hard to follow conversations or TV programmes.

The symptoms of dementia gradually worsen over time, but many things can be done to help manage them. With the right support, many people with a diagnosis of dementia live happy and fulfilling lives for many years.

Some ways of living positively with dementia are described in Section 3.

Memory and reasoning problems may lead people with dementia to become anxious and depressed. Many people find they have problems with their mood, both anxiety and depression, as part of their illness. Mood disorder can itself worsen memory but is treatable. The memory services can provide various medical and psychological therapies in these cases.

Some people with dementia lose their 'drive' and some have problems controlling their emotions. Aspects of the personality may change, such as developing compulsive behaviour or acting differently in social situations. Some people with dementia may also see or hear things that other people do not.

These symptoms do not occur with every form of dementia or in every case. If a diagnosis is made, the memory clinic and your GP will give more information and advice on the symptoms that might develop.





How common is dementia?

It is estimated that over 2,500 people in Southend-on-Sea currently live with dementia. The older the age, the more common it is. In the UK one-in-14 people aged 65 plus has a form of dementia, and one-in-6 people aged 80 plus. The majority of people with dementia are over 75 years old, however, it can occur among younger people.

The main types of dementia are:

Alzheimer's disease, where small clumps of protein, known as plaques, begin to develop around brain cells. This disrupts the normal workings of the brain.

Vascular dementia, where problems with blood circulation result in parts of the brain not receiving enough blood and oxygen.

Dementia with Lewy bodies, where abnormal structures, known as Lewy bodies, develop inside the brain.

Fronto-temporal dementia, where the frontal and temporal lobes of the brain begin to shrink. Unlike other types of dementia, fronto-temporal dementia develops more often in younger people i.e. those under 65 years. It is much rarer than other types of dementia.

Some people have 'mixed dementia', or more than one of the four types.

For more information on all types of dementia please contact - Alzheimer's Society Southend by telephone on [01702 345156](tel:01702345156) or visit the Alzheimer's Society website: www.alzheimers.org.uk

Section 3

Living Well With Dementia

In the early stages, the effects of dementia are mild and many with the diagnosis lead busy, diverse and enjoyable lives. In the later stages, the whole life of the person is affected, and family members close to the person are also much affected.



This section begins with the many ways that people living with dementia can take part in enjoyable, safe and healthy activities, including meeting people in similar situations. It closes by describing the arrangements that we all should make to protect our interests in case we become incapable of making decisions at the end of our lives.

These days a great deal of information is available on the Internet, but of course not everyone has a computer or one that goes 'on line'. This information booklet can provide an alternative way of getting more information, usually a phone number. Remember, though, that many of the organisations in Southend that provide advice to people affected by dementia, will help you access and use the Internet, and all the local and mobile libraries offer free access to computers and the Internet.

People with dementia should remain as independent and active as possible and continue as many of their usual pastimes as they can. If a person with dementia can prepare a drink or snack, or can put the groceries in their place as they have always done, this lifestyle should be maintained and encouraged. Continuing to meet friends and relatives, old and young, is particularly important. Those who have enjoyed going on walks, trips and holidays should continue to do so. There is no reason why people should not still enjoy listening to music, singing, dancing, painting, craftwork or going for a swim. Maintaining your social life makes an important contribution to your continuing wellbeing.

A person with dementia's memory problems may eventually mean that most activities outside the home have to be accompanied, but short walks independently in well-known areas should not be ruled out. Even going to a neighbourhood shop is possible if the shop owner and assistants are briefed and know who to contact if there is a problem. Encouraging people in the neighbourhood to be 'dementia friendly' will also help others. More ambitious trips can be undertaken with careful planning. There is a lot to be said for joining with others who have been affected by dementia to arrange local walks and visits.

Travel and holidays

If a person with dementia has to travel alone and requires assistance, it is important to let the transport company know in advance. Most airports and rail companies offer help to board the train or plane, and will assist with changes and connections. If the person is likely to become

disorientated or distressed during the journey, it is recommended that they have an escort.

The Alzheimer's Society has a factsheet and informative web pages about 'Travelling and going on holiday'.

See www.alzheimers.org.uk/factsheets

Telephone number 01702 345156

The charity Vitalise offers short breaks and holidays at its own centres for people with dementia at various prices. (Vitalise, Shap Road Industrial Estate, Shap Road, Kendal, Cumbria LA9 6NZ).

Tel: 0303 3030145.

Website: www.vitalise.org.uk

Another organisation that offers trips at various prices for small groups and couples affected by dementia is Dementia Adventure. Their focus is on action-packed breaks, and connecting with nature in a fun and fulfilling way.

Tel: 01245 230661

Website: www.dementiaadventure.com

Another useful website is: www.dementiaweb.org.uk/holidays-andtravelling

Driving

A diagnosis of dementia does not result in the automatic withdrawal of the person's driving licence. What matters, legally and practically, is whether the person is still able to drive safely. If you have the diagnosis and wish to continue to drive, the law requires that you tell the Driver and Vehicle Licensing Agency (DVLA). This is done using form CG1 from the DVLA website www.dft.gov.uk/dvla/medical.aspx

Alternatively telephone 0300 7906806 and they will send a copy (the line is open 8am to 5.30pm Mondays to Fridays, and 8am to 1pm on Saturdays).

DVLA recommend that if you are unsure what answers to put down, you should discuss the form with your GP.

Fuller information about the legal situation with regards to driving and practical steps to take is available in an Alzheimer's Society factsheet or on its website. This runs through the factors that should be taken into account when considering whether to stop or continue driving.

If someone with a diagnosis of dementia is unsure of their ability to continue driving, they can take a driving assessment.

An assessment is not the same as a driving test. It is an overall assessment of the impact that the dementia is having on a person's driving performance and safety, and it makes some allowances for the bad habits that drivers get into.

To take a driving assessment, please contact the East Anglian Drive Ability centre on 01842 753029, (in some circumstances a fee is applicable).



Personal finances

Depending on a person's circumstances, financial and age, there may be a number of social security benefits available to those with a diagnosis of dementia and their carer. Examples include:

- Help if your ability to work is limited by ill health or disability [Employment and Support Allowance \(ESA\)](#) has two elements, contributory and income-related
- Help for certain people on low income ([Income Support](#))
- Help for carers ([Carer's Allowance](#)). You may be able to get this if you spend 35 hours per week caring for someone, you're 16 or over and earn less than £102 a week
- Help with housing costs ([Housing Benefit](#)). You can apply for help with the cost of rent whether you get other benefits or not and are in or out of work. [Council Tax](#) discount may apply. Contact your local council tax department for a form. Further information available from the Alzheimer's Society
- [Attendance allowance](#) may be available to people aged 65+ years who need help with personal care. [Personal Independence Payment](#) may be available for people under 65 years who need help with some of the extra costs caused by long-term health conditions or a disability

Neither Attendance Allowance nor Disability Living Allowance are based on income or savings.

The government is changing some benefits and you need to make sure that you have up-to-date information. It is probably best to start by approaching one of the several organisations in Southend that provide advice such as your local Citizens Advice Bureau (CAB) or Age UK or alternatively you can telephone the Department for Work and Pensions' (DWP) general advice line: [0800 88 22 00](tel:0800 88 22 00). If you or a relative have access to the Internet, there is a lot of useful information that can be found on the following websites:

The main government website:

<https://www.gov.uk/browse/benefits>

Age UK:

<http://www.ageuk.org.uk/money-matters/claiming-benefits/>

Carers UK:

<http://www.carersuk.org/help-and-advice/help-with-money>

Turn2us:

http://www.turn2us.org.uk/benefits_search.aspx

Sensible advance planning

Accidents or becoming ill can happen to anyone at anytime. Whether or not this leads to a person going to hospital, it is sensible for everyone to carry information about any medical conditions and dietary requirements. This information is very useful for the people who come to your aid and can prevent delays in decisions about the best treatment.

The Alzheimer's Society and the Royal College of Nursing have produced a standard form for this purpose called [This is Me](#).

You can request a copy at Alzheimer's Society or get one from their website. Alternatively, telephone [01702 345156](tel:01702 345156) to request a copy. People with a diagnosis of dementia are strongly advised to complete this form because it sets out the person's contact details and background.

Every adult should make a will. In the same way, we should all make arrangements to protect our interests should we become unable to make our own decisions about money, property or medical treatment.

The Alzheimer's Society's advice is that, 'if a person has dementia, it is important that they organise their financial and legal affairs while they are still able to do so. This ensures that in the future, their affairs will be set up in a way that they have chosen. The person may want

a friend or family member to help them with this. Make sure that important papers are in order and that you know where to find them, including bank and building society statements, records of mortgage or rent, insurance policies, a will, tax and pension details and bills or guarantees’.

The [Mental Capacity Act 2005](#) made provision for people to choose someone to manage not only their finances and property should they become incapable, but also to make health and welfare decisions on their behalf. They are able to do this through a ‘Lasting Power of Attorney’ for personal welfare. For more information, ask the Alzheimer’s Society for copies of their factsheets 460, *Mental Capacity Act 2005*, and 472, *Enduring Power of Attorney and Lasting Powers of Attorney*.

Other things can be done to ensure that your wishes are followed with respect to social security benefits, managing bank accounts, and your will. To learn more, the Alzheimer’s Society website is a good starting point, or consult them directly.

The [Citizens Advice Bureau \(CAB\)](#) offers advice on these subjects. Its service is free, confidential and independent. Trained CAB advisers offer information and advice on a range of issues including benefits, housing, debt and employment. They may be able to help you resolve your problem or they may provide details of other professionals or organisations. Many CABs have a solicitor able to give free advice, and some also have an accountant, and can often provide information in a range of languages, or refer people to an interpreting service. Please call CAB Southend on [0844 477 0808](#).

Advice booklets

The national Alzheimer’s Society is the leading support and research charity for people with dementia, their families and carers.

The Alzheimer’s Society has produced many ‘factsheets’ about various aspects of living with dementia. Many are available on their website (www.alzheimers.org.uk). (contact details in Section 5).

Other organisations have produced useful online booklets, including:

Living Well with Dementia: The Westminster Guide. Housing 21, London.
www.westminster.gov.uk/workspace/assets/publications/Living-Well-with-Dementia-Oct-10-1292418589.pdf

Living Well with Dementia, NHS Gloucestershire, Gloucester
www.southwestdementiapartnership.org.uk/wpcontent/uploads/living-well-handbook.pdf

Innovations in Dementia, London
www.innovationsindementia.org.uk/resources

Assistive technology - devices to help with everyday living

What is assistive technology?

The term 'assistive technology' refers to 'any device or system that allows an individual to perform a task that they would otherwise be unable to do, or increases the ease and safety with which the task can be performed' (Royal Commission on Long Term Care, 1999). This includes equipment and devices to help people who have problems with:

- speaking
- hearing
- eyesight
- moving around
- getting out and about
- memory
- cognition (thought processes and understanding)
- daily living activities, such as dressing and preparing meals
- socialising

Assistive technology ranges from very simple tools, such as calendar clocks and touch lamps, to high-tech solutions such as satellite navigation systems to help find someone who has gone missing.

What are the benefits?

Assistive technology can:

- promote independence and autonomy, both for the person with dementia and those around them
- help manage potential risks in and around the home
- reduce early entry into care homes and hospitals
- facilitate memory and recall
- reduce the stress on carers, improving their quality of life, and that of the person with dementia.

What technology is available?

There are many different technologies that can be adapted to the needs of someone with dementia. Further information is available in the dementia-friendly technology charter. The charter gives people affected by dementia information on how to access technology. This is available from the Alzheimer's society website www.alzheimers.org.uk

Section 4

Assessment, Support And Advice Services

Anyone concerned about their memory problems should seek the opinion of their GP, and anyone concerned about a relative or friend's memory should encourage them to go their GP. The GP will assess the severity of the problems and the likely causes. If they believe that the patient's problem is dementia, they will refer him or her to the specialist NHS services.

Memory Services in Southend-on-Sea

South Essex Partnership NHS Foundation Trust (SEPT)

SEPT is the main source of dementia assessment and treatment for people aged over 65 years. The [Memory Service](#) aims to provide early assessment and diagnosis so that treatment and support can be initiated quickly. Services are located at Southend Hospital, Sydervelt Centre and the Harland Centre. The Memory Service carries out tests to determine whether a diagnosis of dementia (or other brain disorder) is appropriate. Not everyone who undergoes these tests receives a diagnosis of dementia. For some people given a diagnosis of dementia, there is medication that may slow the progress of the illness. Fuller details of the Trust dementia services are given on its website www.sept.nhs.uk



SEPT also provides specialist services for people with learning disabilities who are diagnosed with dementia and their carers. The Learning Disabilities Team carries out a wide range of assessments and can give a diagnosis of dementia. Anyone with a learning disability who is seriously concerned about their memory problems can consult either their GP or the Learning Disability service on [0300 1230808](tel:03001230808) (SEPT's Contact Centre).

Southend University Hospital NHS Foundation Trust (SUHFT)

A second memory clinic is provided by SUHFT. This clinic specialises in assessing memory for those under 65, people with ongoing physical illnesses and people under the care of the Neurology Department.

Southend-on-Sea Borough Council

Civic Centre, Victoria Avenue,
Southend-on-Sea, Essex SS2 6ER

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www.southend.gov.uk

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