

Patient Information Booklet

Living Well with Dementia



Information and advice for patients diagnosed with memory problems or dementia and their families and carers.

Produced by:
Isle of Wight NHS Memory Service



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SMOKEFREE
Isle of Wight

If you require this leaflet in another language, large print or another format, please contact the Quality Team, telephone 01983 534850, who will advise you.

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INTRODUCTION

This booklet is a guide to the medical, care and support services available for people with dementia on the Isle of Wight. The booklet aims to offer help to those people who are worried about their memory or concerned about a friend or relative and explains where to go to for help and advice.

Dementia is a term used to describe a set of symptoms which include memory and thinking problems. A number of different diseases can cause dementia, the most common cause being Alzheimer's disease. People need good information and support in order to better understand the condition and to maintain an active lifestyle for as long as possible.

This booklet provides information about dementia. It also gives details about other sources of advice and support, including Internet websites, telephone numbers and national and local contacts. The information provided here is for people in the early or middle stages of dementia. For more detailed information or information about the later stages please contact the Alzheimer's Society or the Memory Service (see 'Getting Help' section).

ABOUT DEMENTIA

What is dementia?

The term 'dementia' describes a set of symptoms which include loss of memory, mood changes, and problems with communication and reasoning. These symptoms occur when the brain is damaged by certain diseases, including Alzheimer's disease and damage caused by a series of small strokes. Dementia is progressive, which means the symptoms will gradually get worse. How fast it progresses will depend on the individual person and what type of dementia they have.

You may have noticed problems with your memory, but a doctor may feel that the symptoms are not severe enough to warrant a diagnosis of dementia, particularly if you are still managing well. When this occurs, some doctors will use the term '**Mild Cognitive Impairment**' (MCI). Recent research has shown that individuals with MCI have an increased risk of developing dementia but a diagnosis of MCI does not always mean that the person will go on to develop dementia.

What are the Symptoms of dementia?

- **Loss of memory:** particularly affecting short-term memory, for example forgetting what happened earlier in the day, not being able to recall conversations, being repetitive or forgetting the way home from the shops. Long-term memory is usually still quite good.
- **Mood changes:** may withdraw, sad, frightened or angry about what is happening to them.
- **Communication problems:** including problems finding the right words for things, for example describing the function of an item instead of naming it.

What causes Dementia?

There are many different causes of dementia, the most common are:

- **Alzheimer's disease:** During the course of this disease an abnormal protein called amyloid is deposited around the brain cells. The internal structure of the nerve cells is also damaged. These changes cause the nerve cells to not function properly. Problems of short-term memory are usually the first noticeable sign. Alzheimer's disease typically presents as a gradual decline in function.
- **Vascular Dementia:** If the oxygen supply to the brain fails due to a blockage in the blood vessels, brain cells are likely to be damaged and this can cause the symptoms of vascular dementia. These symptoms can occur either suddenly, following a stroke, or over time through a series of small strokes. This means that decline tends to occur over a series of distinct stages.
- **Dementia with Lewy bodies:** This form of dementia gets its name from tiny abnormal structures that develop inside nerve cells which can cause the brain cells to die. Symptoms can include disorientation and hallucinations. With this type of dementia symptoms can fluctuate on a daily or even hourly basis. This disorder is closely link to Parkinson's Disease.
- **Fronto-temporal Dementia:** In fronto-temporal dementia, damage is usually focused in the front part of the brain. At first, personality and behaviour changes are the most obvious signs.

With all types of dementia, other medical conditions can cause symptoms to worsen.

Who gets dementia?

There are about 800,000 people in the UK with dementia. Dementia mainly affects people over the age of 65 and the likelihood increases with age. However, it can also affect younger people too: there are over 17,000 people in the UK under the age of 65 who have dementia.

It can affect both men and women. Scientists are investigating the genetic background to dementia. In a few rare cases the diseases that cause dementia can be inherited. Some people with a particular genetic make-up have a higher risk than others of developing dementia.

Getting a diagnosis

If you start to notice signs of dementia in yourself or in someone else it is vital that you visit your GP as it is very important to get a proper diagnosis. Visiting your GP will help in ruling out other illnesses that can cause similar symptoms to dementia. Having a diagnosis will mean that your doctors can consider if medication is appropriate for you and you will gain access to a wide range of support. Whether you are someone with dementia or a carer, a diagnosis can help with preparing and planning for the future.

The doctor may carry out a number of tests to check basic thinking processes and the ability to perform daily tasks. They may request further tests, such as a brain scan, blood tests or a more in-depth assessment of memory, concentration and thinking skills.

What Treatments are available?

Most forms of dementia cannot be cured, although research is continuing into developing drugs, vaccines and other treatments. Drugs have been developed that can temporarily alleviate some of the symptoms of some types of dementia. These drugs include the three acetylcholinesterase inhibitors: Donepezil, Rivastigmine and Galantamine. Sometimes these drugs will be given different names please check with your GP if you are unsure. If you are prescribed one of these medications your doctor will discuss side effects, how to take it and what improvements you may expect.

- **Alzheimer's disease:** It is recommended that people in the mild-to-moderate stages of Alzheimer's disease are given treatment with one of the acetylcholinesterase inhibitors. Or in the later stages a different drug such as memantine may be prescribed.
- **Dementia with Lewy bodies:** People with dementia with Lewy bodies may be offered an acetylcholinesterase inhibitor if their non-cognitive symptoms, such as hallucinations, delusions or associated behaviours, are very distressing.
- **Vascular Dementia:** People with vascular dementia will not be offered an acetylcholinesterase inhibitor, except as part of a clinical trial. This is because of a lack of evidence that these drugs are effective for symptoms of vascular dementia. Treatment should be aimed at the underlying cardiovascular (heart and circulatory) problems.

Other medication

Other medications such as antidepressants, antipsychotics and sleeping pills may be prescribed to help with other common symptoms of dementia such as anxiety, depression and hallucinations, although only after other strategies have been tried because these medications can produce side effects in some people that may be detrimental.

Taking large amounts of medication including over-the-counter drugs such as pain killers can at times lead to additional problems. Check with the GP to make sure that you are not taking any drugs that you no longer need. If any drugs are used to relieve behavioural symptoms make sure these are reviewed very regularly by a named person. If you suspect that your medication may be increasing confusion or causing other unwanted side-effects, tell the GP. Also it is good to try to ensure medication is taken as prescribed.

Try to understand the reasons behind the symptoms being experienced as there are often other ways of minimising distress without the use of medication. For example aggression may for example indicate that the person is scared or frustrated. This may be overcome by reassuring them that they are safe, or even distracting them from the issue that is distressing them.

GET INVOLVED IN DEMENTIA RESEARCH

Doing more research is vital to improving the prevention, diagnosis, treatment and care of people with dementia and possibly preventing it. The Dementia and Neurodegenerative Diseases Research Network (DeNDRoN) have a register where you can sign up to be part of this. The service will allow patients and carers to register an interest in research and be matched to studies that may suit them. It will increase opportunities for people to find the right study and help researchers to answer more research questions more quickly.

For more information see 'Getting Help' section for contact details.

- **Join the Research Network:** Carers, former carers and people with Dementia play an integral role in the Alzheimer's Society research programme.
- **Clinical trials:** Research funding organisations and pharmaceutical companies fund research into development of new drugs and treatments that could halt the progression of Dementia and provide a cure in the future.

- **Brains for Dementia Research (BDR):** To fully understand dementia researchers need to study brain tissue. People both with and without dementia can play a valuable role in the future of dementia research by registering as a brain donor.
- **Priority Setting Partnership:** Help set some priorities for the future direction of dementia research, by identifying areas that you feel are important to people affected by dementia. The dementia Priority Setting Partnership aims to identify and prioritise the unanswered questions about dementia from the perspectives of people with dementia, their carers and former carers, health and social care professionals and members of the community This will help direct future research according to what is most important to those affected. This is a project led by the Alzheimer's Society.

If you are interested in getting involved in research the following links may be useful.

www.marc.soton.ac.uk/contact.asp

www.dendron.nihr.ac.uk/south-coast/discover-south-coast-lrn

www.brainsfordementiaresearch.org.uk

www.crncc.nihr.ac.uk/focus_on/dementia

HEALTHY LIVING

Remaining as physically and mentally fit as possible is important for everyone. In this section we will look at tips for maintaining health and well-being.

Exercise

Everyone needs regular exercise, whether or not they have dementia, but people have different ideas on what exercise is. Exercise should take into account the amount of physical activity you have been used to in the past. Try to find a form of exercise that will be enjoyable. Ask your GP, occupational therapist or physiotherapist for suggestions.

Benefits of exercise include:

- Encourages mobility—and therefore, independence—for as long as possible.
- Improves circulation and help prevent stiffness and muscle wasting.
- Aids relaxation, promote a sense of calm and help ensure a good night's sleep.
- Reduce anxiety, stress and depression.

Mental well-being

Mental health and well-being is as important as a person's physical health. Reassurance of still being valued and having a role in the home and family is vital.

Try to avoid doing things that you find stressful and adapt activities as your abilities change. Occupational Therapists can support you in doing this if needed. If mental health needs are not met, you may notice that the person you care for starts to withdraw from every day activities and social events and may become more irritable.

Eating well

Nourishment and hydration are essential in maintaining health. Maintain a balanced diet and regular fluids throughout the day.

- If the person you are caring for is reluctant or forgetting to eat and drink, this can be resolved by keeping finger foods and a drink by their chair and giving regular prompts.
- Constipation is a common problem among older people. It may cause pain, discomfort, and increased confusion. Changes in diet and exercise can help.

If you are concerned that someone with dementia is not eating or drinking enough or is experiencing constipation, please discuss this with your GP who will be able to advise on alternative options.

Regulating temperature

Being cold or too hot for any length of time is a serious health risk. A severe drop in body temperature can cause hypothermia whereas overheating can cause dehydration and trigger other medical problems. The person you are caring for may feel the cold or heat far more than you do. At times they may not realise it or may be unable to tell you. Try to complete regular checks and make adaptations to the environment as needed.

Smoking and alcohol

- Smoking can significantly increase risks for people with dementia. It can be very difficult to give-up and some people may not want to quit. Your GP can support you with this.
- Alcohol can increase confusion and doesn't mix well with certain medicines. It is advised that no more than 2 – 3 units (e.g. a small glass of wine or half a pint of beer) of alcohol should be drunk per day. People who have dementia related to past alcohol use should not drink alcohol.

ASSOCIATED MEDICAL PROBLEMS

Hearing problems

Hearing problems can add to feelings of confusion and isolation. If you think that the person you are caring for has a hearing problem, ask their GP for a referral for a hearing test. The test and hearing aids, if needed, are free on the NHS.

Eyesight

Problems with sight can also contribute to confusion in people with dementia, making it harder to recognise people or objects. Optometrists have special techniques for assessing sight, even for people in the later stages of dementia. They should also check for cataracts and glaucoma (both of which can lead to blindness if left untreated) as well as for certain other medical conditions.

If you know someone with dementia who has sight problems, you may need to tactfully remind them to wear their glasses and check that their lenses are clean.

Dental care

It is important to have regular dental check-ups to make sure there are no problems with teeth, gums or dentures. Any pain or discomfort will cause distress and may lead to difficulties with eating and drinking.

Foot care

Healthy feet are essential to remaining mobile and active. Try to make sure well fitting comfortable shoes are worn and any problems with the feet are addressed by a registered chiropodist as soon as possible. If feet become painful, swollen or discoloured, contact your GP.

SELF MANAGEMENT AND COPING STRATEGIES

As dementia progresses, the person you are caring for may experience problems with completing every day activities. In this section we will give some tips that may help to maintain independence. Trying some of these strategies may help to reduce problems in other areas; such as restlessness, anxiety or repetitive questions.

- **Routine:** Try to establish and maintain a firm daily and weekly routine. This will help the person to know what day or time it is as well as what is happening next.
- **Using familiar tasks:** It is important to maintain ability in familiar activities. Taking up new hobbies that require learning of new skills may be difficult and stressful.
- **Encourage independence:** Sometimes when a person starts to find a task difficult, they can be helped by a simple prompt or by their carer breaking the task into smaller chunks. Remain calm, reassure and encourage them to do as much as they can for themselves.

Safety first

Sometimes the person with dementia will not be as aware of risks as others.

Making some basic changes in the home can make a big difference and prevent injury in the future. These include:

- Securing loose mats and rugs.
- Clearing walkways.
- Improving lighting around the home.
- Ensuring that smoke alarms and gas alarms are working.

Check how the person is managing the stairs and steps in the home. Additional rails can be fitted by the Red Cross or more extensive jobs can be completed by the community Occupational Therapy team (see 'Getting Help' section).

Common problems and some strategies

Not knowing where things are in cupboards

- Have specific places for everyday items.
- Label cupboards using written and picture signs.
- Keep commonly used items where they are clearly visible e.g. tea/coffee/squash/cup in glass fronted cabinets/shelves or left on worktop.

Being distracted from one train of thought

- Try not to focus too much on upcoming events as this can provoke anxiety.
- Focus on one task at a time. If needed, break a task down into smaller chunks.
- Don't feel you have to do too much. What are the most important things you want to do.
- Reduce distractions e.g. Turn off TV, radio, avoid large crowds.
- Try to relax. Slow down and give yourself plenty of time.
- A quick prompt from another person can be very useful.

Writing a list and then losing it

- Use a bright coloured note book that can be kept with you, whiteboard, Dictaphone, computer, mobile phones. Consider what you have used in the past.
- Have a specific place for keeping lists / important messages.

Managing the telephone

- Get a big buttoned telephone.
- Store telephone numbers with a picture / name of the person next to the number.
- Log telephone calls; write down messages and who called.
- Make notes on what you want to say before you make a call.
- Put an address and phone label on the phone for emergencies.

COMMUNICATION

You may feel under pressure because you can't cope as well as you used to. You may feel that you are losing your independence and your privacy, or that you are being judged for making a mistake. A change in routine, a noisy environment or too many people can also affect your ability to communicate.

Here are some hints to aid communication:

- Use visual aids like photo-albums and familiar items to provoke conversation and maintain attention.
- Ensure language is clear and to the point.
- Ensure you are facing your relative and clearly within their eye-line when talking to them.
- Don't argue and confront. If you don't agree with what the person is saying, try to move onto a different topic or offer a distraction.
- It is important that if a person is expressing something that they are feeling upset or frustrated about that it is acknowledged as a concern by the caregiver even if the caregiver does not feel it is a problem. For example say 'I can see that this is upsetting you'.
- Make sure you have their attention, gently touch the person's arm and say their name.
- Laugh! Try to see the funny side of life and enjoy the joke together.
- Allow plenty of time for the person to take in what you say and to reply.
- Don't ask questions that test the person's memory ('Who am I?' or 'How old are you?')
- Try not to confuse or embarrass the person by correcting them bluntly.

A smile, touch or gesture can be very important. Sometimes just holding the hand of the person you are talking to can be very reassuring.

RELATIONSHIPS AND SEXUALITY

If you are caring for a person with dementia who is close to you, your relationship will change as time passes. You may even experience feelings of grief and bereavement as the illness progresses without even realising it.

Living with dementia can put a strain on relationships, particularly if they are in the early stages of dementia. However there is much you can do to keep the relationship positive.

- Spending time apart socialising, or following satisfying or creative pursuits can boost each partner's self-esteem and give you something to share with each other.

Everyone has the right to express their sexuality without fear of judgement. This is no less the case for people with dementia. Relationships may change as the disease progresses and intimate relationships can take many different forms. Sex is not important for everyone.

Over time, some partners develop forms of physical intimacy, such as touching, that do not correspond with what they had previously thought of as 'sex'. By keeping an open mind about what 'sex' and 'intimacy' mean for you and your partner, you will be well placed to focus on the pleasurable aspects of your relationship and less worried by the rest.

It is also important that you both have plenty of support to help you adjust to any changes. If you are worried or upset by something, discussing your feelings and concerns with someone who understands can often help. More information can be obtained from the Alzheimer's Society.

COGNITIVE STIMULATION THERAPY

CST aims to engage and stimulate people in a friendly and enjoyable group setting. The research on CST shows that it improves thinking abilities as well as general wellbeing.

Cognitive Stimulation Therapy (CST) is an evidence based therapy for people with mild to moderate Dementia. CST consists of 16 sessions of themed activities over 8 weeks. A typical session would involve an introduction, a discussion about current news stories and a programme of activities arranged around a particular theme.

The Memory Service offers CST as a part of the treatment following diagnosis. Please ask for further information about this if it is something that you feel you would be interested in.

ASSISTIVE TECHNOLOGY

Also known as Telecare these are devices to help with everyday living. Assistive technology can help you to overcome problems that present in every day living to maintain independence and reduce risks.

What is assistive technology?

'Assistive technology' refers to any device or system that allows you to perform a task that you would otherwise be unable to do, or increases the ease and safety with which the task can be performed. 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 technology is available?

There are many different technologies that can be adapted to the needs of someone with dementia. This section mostly focuses on electronic devices but simpler equipment, such as tap turners, are also assistive technology devices.

Examples:

- Aids that give electronic reminders – Recorded alerts to remember keys / have lunch.
- Clocks and calendars – Calendar clocks can be helpful for people who forget which day it is. Try to find one that shows the date and day of the week too.
- Medication aids – Dosette boxes with days of the week on or automatic pill dispensers.
- Locator devices – Aids that help you locate easily mislaid items at the touch of a button.
- Aids for reminiscence and leisure – Software is available on the Internet to evoke memories and stimulate conversation.

Other aids are also available to help reduce many different risks, such as:

Floods, extreme temperatures (home getting too hot / too cold / sudden changes in temperature), gas being left on or leaking, falls, getting up in the night or leaving the home with the possibility of becoming lost or disorientated.

Where to get further information?

- Where there is a specific risk that you think can be addressed through Telecare, further information can be gained through Community Occupational Therapy or Social Services (please see useful contacts section).
- Wightcare offers a high quality 24 hour emergency support to Island residents. For further information call 01983 821105.
- Alzheimer's Society sells a range of assistive technology products through the online shop at alzheimers.org.uk/shop
- Many of these devices are now available on the high street for example in chemists or hardware stores.
- AT Dementia is an organisation that provides information about telecare support and also produces a self-assessment guide that can help people identify which assistive technologies may be of use to them (see useful websites section).
- The Independent Living Centre offers a free and impartial service to Island residents to help them to find out about the aids for daily living that could enhance their lives and enable them to continue to live independently at home.

It is always best to have a discussion with an expert about your individual needs prior to purchase because not every device is suitable for everyone and people will respond in different ways.

FINANCIAL AND LEGAL AFFAIRS

After a diagnosis of dementia, it is important that you organise your financial and legal affairs while you are still able to do so. This ensures that in the future, your affairs will be set up in a way that you have chosen.

Make sure that all important papers are in order and that you know where to find them. These papers might include bank and building society statements, records of mortgage or rent, insurance policies, a will, tax and pension details and bills or guarantees.

Lasting Power of Attorney (LPA)

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 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.

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 for the attorney to give or refuse consent to medical treatment if this power has been expressly given in the LPA. 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 advance decision refusing treatment, thus giving the attorney power to make the decision.

Both forms of LPA can only be used once the form is registered at the Office of the Public Guardian and you no longer have the capacity to make decisions about your own welfare.

Do I need a solicitor?

You do not have to seek legal advice but an LPA is a powerful and important legal document and you may wish to seek advice from a legal adviser with experience of preparing them. There are likely to be costs involved.

Advanced Decisions

You may be concerned about how decisions about your medical treatment would be made if you lose ability to decide for yourself. You may fear that you will be forced to receive life-sustaining or life-prolonging treatments long after you are able to achieve an acceptable level of recovery, length of life or quality of life.

- An **advance directive** is intended to be a binding refusal of certain kinds of medical treatment for example a do not resuscitate order, specified by the individual.
- An **advance statement** is a statement of general beliefs and aspects of life that you value. It may reflect individual aspirations and preferences, and is sometimes called a 'personal values history'. The statement can be used to help health professionals and others, such as family members, to decide what sort of treatment the person would want if they were unable to communicate their wishes. However, an advance statement would not bind healthcare professionals to a particular course of action if it conflicted with their professional judgement.

How do I draw up an advance decision?

You can draft an advance decision yourself using your own words. Unless it relates to life sustaining treatment, an advance decision can be made verbally. However, it is advisable to make your advance decision in writing to ensure that the medical professionals are aware of your wishes and that they are understood correctly.

Wills

Everyone should make a will as this ensures their possessions go to the people they choose. If you have a diagnosis of Dementia you should speak to a solicitor as soon as possible—although it is still possible to change or make a will after diagnosis—a solicitor will advise on this and take medical advice if necessary. People who no longer have capacity to make decisions cannot make a will or alter one already made.

Appointeeship

This is a procedure whereby the benefits you receive can be managed by someone else on your behalf if you are unable to do this for yourself. This is arranged through someone becoming an appointee. If someone is to become an appointee, they must contact their local Department for Work and Pensions Office (DWP) explaining why affairs can no longer be managed independently. If possible, the appointee should be a close relative or someone who knows you very well such as a good friend, neighbour or carer.

An appointee is only able to deal with your income from benefits.

BENEFITS

It is very important to check that you are claiming all the benefits you are entitled to. To qualify for any benefit, you will have to meet certain conditions. These vary according to the type of benefit. Some benefits depend on whether or not you have paid national insurance contributions over a period of time, some on the amount of your weekly income and savings, and some on the practical effects of a disability.

Disability Living Allowance (DLA)/Personal Independent Payment (PIP)

If you have care and/or mobility needs before you are 65 you should claim the DLA/PIP. You must be under 65 when you make your first claim. However, once awarded, DLA/PIP can be paid after the person is 65.

Attendance Allowance

If your care is to start after the age of 65, or you have not made a claim until then, you should claim Attendance Allowance. This is assessed based on your personal care needs.

The amount you receive for either Attendance Allowance or DLA/PIP depends on your personal situation. It may include supervision of, or help with activities such as washing, dressing, eating, going to the toilet, turning over or settling in bed, taking medication, or social or recreational activities.

The DLA/PIP also has a mobility component that can be claimed by people who are aged under 65 years and have difficulties getting out and about.

For more information on the benefits you receive see 'Getting Help' section.

DRIVING

Having a diagnosis of dementia is not in itself a reason to stop driving, what matters is whether you can continue to drive safely.

If you have been given a diagnosis of dementia but want to continue driving, **you must inform the DVLA**. If you do not tell the DVLA about your diagnosis you are breaking the law. The DVLA, once informed, will send out a questionnaire and ask for permission to approach your Psychiatrist or GP for information. They can request that you take a driving assessment. You should also inform your insurance company of the diagnosis, as not doing so could invalidate cover in the case of an accident. The Psychiatrist who refers you for your first assessment will discuss this with you in more detail and answer any questions you might have.

When the DVLA decides that the person must stop driving

If, following its medical enquiry, the DVLA decides that you cannot continue driving, you must return your driving licence to the DVLA. However, there is an appeal process. A formal appeal must be lodged with the Magistrate's Court within six months.

Encouraging someone to stop driving

- Acknowledge how difficult it may be for them. They may have relied on driving as their main means of transport for much of their life, and may feel unhappy about losing some of their independence. Encourage them to take charge of their new transport arrangements – perhaps by getting details and timetables of local transport services.
- Highlight alternatives to driving.

ALTERNATIVES TO DRIVING

Bus pass: This entitles people aged 60 or over and people with certain disabilities to travel off-peak free of charge on local bus services anywhere in England.

You can request an application for a bus pass from the local council by contacting them on 01983 821 000 or at www.gov.uk/apply-for-elderly-person-bus-pass

Blue Badge: The Blue Badge scheme helps you park closer to your destination if you or the person you are driving is disabled.

You can request an application for a blue badge from the local council on 01983 823 340 or emails them at blue.badge@iow.gov.uk. You can also complete the application online at <https://www.gov.uk/apply-blue-badge>

Optio Voluntary Car Service: This service is available for people who have difficulties with accessing public transport.

It can be used for important trips such as medical appointments, getting to day centre or therapeutic activities, visiting relatives or shopping.

It consists of a network of volunteer drivers using their own cars.

There is an annual fee to use the service and after this is paid the drivers will charge 45p per mile payable to the driver on each trip (this cost may change). The driver will provide you with a receipt.

Hospital care service: This service is run by volunteer drivers, using their own cars, who are able to collect patients for appointments. Car service drivers have **no medical training** and will not carry specialist equipment. There is a charge to use this service based on the distance of the journey and payment is made to the driver at time of travel.

If you want to book this service please tell the driver at the time of booking the appointment and ask them to forward you information on how costs can be reimbursed.

CARER SUPPORT

When you are caring for someone with dementia, sometimes it's easy to ignore your own needs, but taking care of your own health and wellbeing will help you cope with the caring role and maintain your relationship with the person you are caring for.

- Try to take time for yourself, even if it's only for a short period each day to have a cup of tea and read the paper, call a friend or get a breath of fresh air.
- Try to maintain those activities away from the home that you have always found enjoyable – e.g. meeting with friends or getting your hair done.
- If friends and family offer to help, take them up on this to enable regular breaks to recharge your batteries. You don't have to cope alone.
- Ask Social Services about what options there are for carer support. This may be regular care in the home, day care or a period of respite in a care home for the person with Dementia. As a carer you are entitled for an assessment of your own needs through Social Services.
- If you find that you are needing to assist the person you are caring for in mobility or transfers request a referral to Physiotherapy or Occupational Therapy who can help to reduce the need for moving and handling.
- Have regular check-ups with your GP and if at any time you start to feel low in mood discuss this with them. There are options and it is best if these are explored at an early stage.

Remember all of advice provided in the self management section about maintaining health and wellbeing also applies to you. This includes eating well and staying hydrated, taking time to do things you enjoy and getting enough sleep. If you feel that your ability to do any of these things is affected by your caring role please speak to your GP.

GETTING HELP

- During office hours contact the care manager if you have one – if you do not have a Care Manager or are unsure who they are call the Duty Team on 814980.
- For emergencies out of hours—including weekends and bank holidays—ring Wightcare on 01983 – 821105
- For problems with your physical health call your GP or the urgent NHS number 111.

NHS – Memory Service

The Memory Service is a specialist service for people who are having problems with their memory, or other areas of their thinking.

What may I expect from the service? Initially an assessment by a doctor to find out what the problem is and to see whether you need any more tests. You may then be referred to one of the following: Carer Support, Occupational Therapy, Cognitive Stimulation Therapy groups, Clinical Psychologist, Post Diagnostic Counselling, Information & Advice.

Continuity of Care: Although you may not need to be followed up for very long by the memory service after your diagnosis, we will make sure that you know where to go for support if you need it.

Social Services

Social services can allocate a care manager where appropriate, and may be able to assist with personal budgets, help to facilitate personal care, respite, carers assessments and will support you as your needs change. In some cases they will support you in applying for benefits such as Attendance Allowance.

Alzheimer's Society

The society provides an information and support line and a Dementia Adviser Service for people living with dementia, their carers, friends and family, professionals and anyone wishing to make enquiries about dementia. The Dementia Advisors can be contacted on 07738854632 or 07738854629 and the National Helpline is 0300 222 11 22.

They also provide a support group at Orchard House (189 Fairlee Road, Newport) providing support, information and activities for people living with Dementia and their carers. Held 3rd Wednesday of the month, 10:30am – 12:30. See useful contacts.

Alzheimer's Café

An Alzheimer's Café is a regular social and information event for people experiencing Alzheimer's disease and other forms of dementia, to visit with their families and carers. The concept of a café, provides a relaxed atmosphere where people can enjoy a drink and something to eat as well as listen to a presentation about key aspects of the disease and particularly its emotional consequences for carers and families. The Alzheimer's Café also provides dementia education for family carers and others that are interested in the disease. Cafés run across the Island:

- Ryde: 1st Friday of the Month, 11:30am–2pm.
- Sandown: 2nd Tuesday of the Month, 6pm–8:30pm.
- Freshwater: 3rd Wednesday of the Month, 2pm–4:30pm.
- Newport: Last Thursday of the Month, 6pm–8:30pm.
- Ventnor: 1st Wednesday of the Month, 2pm–4:30pm.

See useful contacts for more information.

Wightcare

Provides high quality professional support to enable Island residents to live independently in their own homes. They provide a 24 hour call system should you require assistance, giving you peace of mind. They also provide a 'Carers Alert Card', this is for anyone who is a carer. It identifies that there is someone who needs help in the event of the carer having an accident, this is a free service.

Data Link

This is a voluntary scheme run by the Lions Club whereby a bottle containing medical and personal information is placed in your fridge and can be used by the emergency services if you are unable to give the information yourself. Bottles can be obtained from GP surgeries, Chemists, Council Offices or contact your local Lions Club.

Riverside Centre

This centre provides a respite service on a Saturday. They also have various activities during the week which may be suitable for some people. Call: 01983 – 822209

USEFUL CONTACTS

- **Age UK:** Provides information, support and advice for older people in the UK. Call: 01983 – 525282 Or visit their website: www.ageuk.org.uk/isleofwight
- **Alzheimer's Café:** Call 07849181477 or visit www.alzheimercafeiow.org.uk for more information.
- **Alzheimer's Society:** Also provides lots of support and information. Call: 0300 222 11 22 OR visit their website: www.alzheimers.org.uk
- **Benefit Enquiry Line:** National advice and information about benefits. Call: 0800 882200 OR visit their website: www.direct.gov.uk/benefits
- **Carers UK:** For information and advice, Call 01983 – 533173
- **Community Occupational Therapy:** 01983 – 534520
- **Continence Advice:** Speak to your GP or district nurse. Pads will be provided free of charge if there is a significant problem.
- **Council Tax Benefit:** It may be possible to pay a reduced council tax. Call: 01983 – 823950 / 821000
- **Disabled Toilet Key:** Can be collected from County Hall reception for a small charge.
- **Our Health:** Our Health opens the door to a wealth of information on stroke and dementia. Visit the website: www.ourhealth.southcentral.nhs.uk
- **Pensions:** For help with your pension call 0845 60 60 265
- **Red Cross:** The British Red Cross provides a wide range of services throughout the Island. Call: 01983 – 522718
- **Social Services:** 01983 – 814980
- **Memory Service:** 01983 – 534411
- **Wight care:** 01983 – 821105
- **Independent Living Centre:** 01983 – 241494
- **Attendance Allowance:** 0845 712 34 56

Valuables should not be brought into the hospital. If patients have to bring in valuable items they should ask a nurse to store them safely and request a receipt for the items. You may not be able to have the valuable items returned if the time of discharge from hospital is out of hours.

We are sorry but the Trust cannot accept responsibility for loss or damage to items not given for safe keeping.

You can get further information on all sorts of health issues through NHS interactive available through Sky TV or online at: <http://www.nhsdirect.nhs.uk/>

For Health advice and out of hours GP service please call the NHS 111 service on **111**

We value your views on our service

If you wish to comment on the care which you, your relative or friend has received, we will be pleased to hear from you. Please speak to the person in charge of the ward, clinic or service in the first instance or ask them to contact the Quality Team. If you wish to contact them directly, telephone on **01983 534850**.

Alternatively you may prefer to write to:

Chief Executive
Isle of Wight NHS Trust
St. Mary's Hospital
Newport
Isle Of Wight
PO30 5TG

You can also share any concerns you have about our services with the Care Quality Commission (CQC) on **03000 61 61 61** or at enquires@cqc.org.uk

All NHS sites are no smoking areas.

If you would like help and advice to stop smoking please call: Freephone **0800 169 0 169** to talk to the NHS Smoking Helpline.