

# Caring for Dementia



## Dementia Carers' Pathways National

Authors David Light and Jim Delves

## Contents

Foreword: .....	3
Section 1: Diagnosis and Understanding Dementia .....	4
Section 2: General Information .....	6
Section 3: Carer Support .....	12
Section 4: Looking after Yourself .....	15
Section 5: Carers Rights and Assessments .....	18
Section 6: Carer Training .....	20
Section 7: Financial and Legal Implications .....	21
Section 8: Benefits .....	24
Section 9: Understanding Domiciliary Care .....	26
Section 10: Understanding Residential Care .....	27
Section 11: Counselling .....	29
Section 12: Glossary .....	31
Section 13: Telephone Numbers, Websites and Emails .....	33
Section 14: Factsheets and Leaflets .....	36
Appendix i: Emergency Details of Cared for Person .....	39
Appendix ii: Reference Sheets .....	40
Useful Telephone Contact Numbers	
Record of Medical Treatments and Incidents	
Record of Telephone Calls and Conversations	
Notes: .....	43

## Foreword

This document is designed to bring the information you will find useful in your role as a carer of any age group. It has been organised into sections around important details you will need to know along your pathway.

It is important that you do not allow the information to overwhelm you by trying to absorb it all at once. We recommend that you refer to the Dementia Carers' Pathways when you have a specific problem or have a subject that you wish to know more about. The document is designed to direct you to an organisation where you will be able to find the Help and information you require.

As we develop the National Dementia Carers' Pathways, your opinions and comments would be welcome to help us in keeping this information up to date.

**Please contact:** [info@carerspathways.org.uk](mailto:info@carerspathways.org.uk) [www.carerspathways.org.uk](http://www.carerspathways.org.uk)

## Disclaimer

The content of this guide has been checked for accuracy at the time of publication. It is designed to provide helpful information and signpost organisations and services that may be of help.

It should not be used as a basis for taking, or not taking, any specific course of action in relation to a person's care. The inclusion of organisations and services is for information purposes only and does not constitute endorsement of any kind by the authors or the organisations supporting the publication.

Always consult a qualified professional about your own care, the care of a loved one or a friend.

Hard copies of the National Dementia Carers' Pathways can be purchased. For a Quotation

**Please contact:** [info@carerspathways.org.uk](mailto:info@carerspathways.org.uk) [www.carerspathways.org.uk](http://www.carerspathways.org.uk)

## Section 1: Diagnosis and Understanding Dementia

### Diagnosis

Because you are reading this you, or someone you care for, will have had a clear and early diagnosis of an illness which might lead to dementia. The importance of an early diagnosis cannot be over emphasised.

An early diagnosis is essential to:-

- Access advice, information and support from social services, voluntary agencies and support groups.
- Allow the person with dementia to plan and make arrangements for the future.
- Identify the type of dementia. This is becoming increasingly important as drugs for treating different conditions become available.

A doctor should have eliminated any physical causes which might mimic a symptom of dementia. Such causes could include a urinary tract infection, chest infection, substance abuse (drugs or alcohol) or mental health conditions such as severe depression.

During the course of dementia your main point of contact for NHS help and support will be your doctor (GP) who will be able to help you access a range of services, including specialist community services that provide individual assessment, interventions and support, including memory clinics. You will find extensive references to other services throughout this Dementia Carers' Pathways booklet.

### Understanding dementia

Although widely quoted the term dementia, technically, does not describe an actual illness. It describes a set of symptoms which might be brought about by one or more illnesses which might affect the brain. These symptoms might involve significant short term memory loss, disorientation or mood swings.

Unfortunately, dementia is progressive and currently there is no positive cure. Drugs are constantly being developed to modify the symptoms. How fast dementia progresses will depend upon the individual. Each person is unique and the course of their dementia will take an individual pathway.

Research has shown that the three main types of illness which may lead to dementia are:-

#### Alzheimer's disease

Alzheimer's disease, first described by the German neurologist Alois Alzheimer, is an 'Organic Degenerative Disorder' affecting the brain. During the course of the disease `plaques and tangles` develop in the structure of the brain, leading to the death of brain cells.

We also know that people with Alzheimer's have a shortage of some important chemicals in the brain. These chemicals are involved with the transmission of messages within the brain. Alzheimer's is a progressive disease which means that gradually, over time, more parts of the brain are damaged, as this happens the symptoms become more severe.

## **Vascular dementia**

To be healthy and function properly, the brain cells need a good supply of blood. The blood is delivered through a network of blood vessels called the vascular system. If the vascular system within the brain becomes damaged and the blood cannot reach the brain cells they will eventually die. This can lead to the onset of vascular dementia.

There are a number of conditions that can cause, or increase, damage to the vascular system. These include high blood pressure, heart problems, high cholesterol and diabetes. It is therefore important that these conditions are identified and treated at the earliest opportunity.

## **Dementia with Lewy bodies**

Dementia with Lewy bodies is a progressive disease. This means that over time the symptoms will become worse. In general, dementia with Lewy bodies progresses at about the same rate as Alzheimer's disease, typically over several years.

People with dementia with Lewy bodies may display some symptoms of both Alzheimer's and Parkinson's disease.

- They often experience the memory loss, spatial disorientation and communication difficulties associated with Alzheimer's and Parkinson's diseases.
- They may also develop the symptoms of Parkinson's disease, including slowness, muscle stiffness, trembling of the limbs, a tendency to shuffle when walking, loss of facial expression and changes in the strength and tone of the voice.
- They often experience the memory loss, spatial disorientation and communication difficulties associated with Alzheimer's and Parkinson's diseases.
- They may also develop the symptoms of Parkinson's disease, including slowness, muscle stiffness, trembling of the limbs, a tendency to shuffle when walking, loss of facial expression and changes in the strength and tone of the voice.

There are also symptoms that are characteristic of dementia with Lewy bodies. People may:-

- Find that their abilities fluctuate daily, even hourly.
- Faint, fall or have 'funny turns'.
- Experience detailed and convincing visual hallucinations, often of people or animals.
- Fall asleep very easily by day and have restless disturbed nights with confusion, nightmares and hallucinations.

### **Obtain information, factsheets and leaflets from:-**

<b>Alzheimer's Society</b>	<b>National Telephone Dementia helpline</b>	<b>020 7423 3500 0845 300 0336 <a href="http://www.alzheimers.org.uk/factsheets">www.alzheimers.org.uk/factsheets</a></b>
----------------------------	---	---

**For further details see Section 13 (Telephone numbers etc) & Section 14 (Factsheets etc).**

## Section 2: General Information

### Emergency Duty Team Carers support (Out of Hours)

To obtain details contact your County Council or Unitary Authority.

### Important personal information

To assist you on your pathway, record sheets are available at the back of this booklet, to record the following information:-

- Emergency telephone contact numbers, leave by the telephone for sitters etc.
- Your own quick reference telephone numbers
- A record of all telephone calls, dates, organisations, what was said and the name of the contact (this may be valuable at a later date)
- A record of the cared for person's medical treatment (this may be valuable at a later date)

If you and the cared for person use a mobile telephone, enter your IN CASE OF EMERGENCY (ICE) telephone numbers in the 'address book', numbering ICE 1, ICE 2, ETC., in order of your preference. Emergency services personnel will always look for information under this entry. In case the cared for person wanders or becomes lost, put emergency contact names, telephone numbers in their handbag, wallet or pocket. Check to see if the local Authority operates a "Safely Home Scheme"

See also the Personal Tracker System Section 2 and Carers Alert Card Scheme in Section 3.

### Message in a bottle

The system works by storing the cared for person's details in clearly labelled plastic bottles. These may be kept in the refrigerator and in the glove box of their vehicle. Matching labels, known to the emergency services, are displayed in their house, on the outside of their refrigerator door and on the inside of their front door, placed so it is not visible from outside. The label is also displayed on the dashboard of their vehicle. This ensures that the essential information is readily available to the emergency services should the cared for person suffer an accident, sudden illness or is involved in a fire. Vital information is available, not only to identify them but also to advise on relevant illnesses, allergies, medication and emergency contact addresses.

**Obtain message bottles from your doctor's surgery, pharmacy, Age Concern, Neighbourhood Watch, Council Offices or telephone the Lions Club.**

### Emergency Details of Cared for Person

Go to Page 39 Appendix i: Fill in form and leave in a prominent position. ie. By the telephone.

### Managing your medicines

Use a tablet dispensing container (memory aid container) to help you to remember when to give prescribed medication. Containers are available to cover a week, either, twice a day, morning and evening, or four times a day, morning, lunchtime, teatime and evening. The container is refilled once a week. Tablet dispensing containers are available at your pharmacist. It is very important to make sure that you put the right medicines in the correct compartment of the container. If necessary keep all medicines out of reach of the cared for person in a cupboard or under lock and key. Under certain circumstances, the dispensing chemist will provide medicines on a week-by-week basis, in the form of a fully labelled 'blister pack'. This helps to avoid any under or overdosing of medicines.

### Maintaining a daily routine

It is important that you try to maintain a sense of routine and continuity for the cared for person and, if possible, that they have an awareness of this. For example regular meal times etc. A list of the day's activities for the cared for person, is very useful in helping to maintain contact with day to day life. This is easily achieved by means of a white board or a written list in a known position, for example, in the kitchen.

## Book of my life

Make a "Book of my Life", for the cared for person. The purpose of the book is to give information of life experiences, relationships, preferences and unique personality of the cared for person that will be available to inform staff in hospitals or care settings. It could contain information about their date of birth, schools (where and when), employment, likes and dislikes, their dietary needs, daily and weekly routines, habits, interests and hobbies. A photograph album of now and in past is another idea. The list is endless, put in your own ideas.

## Memory box

A suitable plastic, wooden or cardboard box can be used. Items from the past of the cared for person can act as a memory aid. The items can show who the person is and what they have achieved in their life. Anything with a personal memory that will stimulate them and that they can relate to is ideal. Objects from the past, family heirlooms, household or personal items with a sentimental value, photographs, medals. Do not include anything sharp or pointed. Add items to the box as time progresses.

## Sources of information

- Age UK (Find an office near you) **Telephone 020 8765 7200**
- Alzheimer's Society **Telephone 01392 368885**
- Citizens Advice Bureau (CAB) (Find a Bureau Near you) **Telephone 03444 111 444**
- Council, District Council or Unitary Authority

The following three publications are very informative and well worth reading:-

### Who Cares?

Can be obtained as a download from the Department of Health publication department  
**Publications department** **Telephone 0300 1231 002**  
**www.orderlinedh.gov.uk**

### Right Care Index

Right Care Index is a U.K. directory for health and social care. It is aimed at assisting the public in their search for care and to enhance and individualise their lifestyles. The solutions offered fall in line with the governments "personalisation agenda".

For a comprehensive listing of services from:-

**Right Care Index** **Telephone 01872 321327**  
**www.rightcareindex.com**  
**Email: mail@rightcareindex.com**

### Still Going Strong

Can be obtained free from The Mental Health Foundation publication department  
**Publication department** **Telephone 0207 8031 100 / 08457 909 090**  
**Email: mhf@mhf.org.uk**

### Information Factsheets and leaflets

Obtain information leaflets from the racks at doctors' surgeries, hospitals and clinics. These leaflets are a good source of information on a range of conditions and services.

Additional sources of information can be obtained from:-

- Section 13 (Telephone numbers, websites and email address)
- Section 14 (Factsheets and leaflets)
- County Council, District Council or Unitary Authority

### Dementia Roadmap

The Dementia Roadmap provides high quality information about the dementia journey alongside local information about services, support groups and care pathways to assist primary care to support people with dementia and cognitive impairment, their families and carers.

**For obtain details visit** **Dementia Roadmap**

## **The National Dementia Strategy**

The National Dementia Strategy is a government backed initiative to raise awareness of dementia. The Strategy sets out 17 recommendations that the government wants the NHS, local authorities and others to take to improve dementia care services. The recommendations are focused on three key themes of:

- Raising Awareness and understanding
- Early Diagnosis and support
- Living well with dementia

**For details visit**

**National Dementia Strategy**

## **Social care**

Your County Council or Unitary Authority is responsible for many social care services in your area through its Adult and Community Services Directorate. The single point of contact for information and to access services is Care Direct which can be contacted about health and social care for adults, help for older people vulnerable adults their carers and the registered disabled.

**To obtain details contact your County Council, District Council or Unitary Authority.**

## **Carers**

Becoming a member of a local Carers group may provide you with:-

1. Access to a Flexible Breaks Grant
  - Assistance to attend your local carers' forum
  - Benefits check
  - Carers' newsletter
  - Contact details for social or health care
  - Carers Alert Card Scheme
  - Free carers information pack
  - Support groups
  - Take-a-Break service
  - Training opportunities

**To obtain details contact your County Council, District Council Direct or Unitary Authority**

## **Registration of people with disabilities**

Anyone who has a disability can apply to go on the register. Local concessions may be available.

**To register, contact your County Council, District Council or Unitary Authority**

## **VAT relief**

There is no VAT payable for registered disabled people on certain goods and services. H M Revenue and Customs (HMRC) reference notice 701/7 gives information on relief for disabled people.

**To obtain details contact HM Revenue and Customs**

## **Getting out and about**

### **Blue Badge parking scheme**

The Blue Badge parking scheme provides a national range of parking concessions for disabled people with severe mobility problems who have difficulty using public transport, who travel either as a driver or passenger in a vehicle. The badge belongs to the person, not the vehicle.

**For information contact your District Council or Unitary Authority.**

### **Discount parking**

Residents who are Blue Badge holders, may be entitled to discount parking in their County Council or Unitary Authority car parks.

**For information contact your District Council or Unitary Authority.**



## **National Radar key**

The National Radar key system offers independent access to toilets for people with disabilities. A Radar key for use of the toilets, a list of toilets for the disabled in your District Council area and where to obtain a key is available from your local District Council or your Unitary Authority.

**For details contact your District Council or Unitary Authority**

## **Community Transport**

Helping you get out and about. Community Transport is the provision of non-profit making transport for the many people who may live miles from the nearest bus route or are unable to afford taxi fares or are physically unable to use the public transport services provided.

Community Transport can include:-

- Community Bus Schemes
- Community Car Schemes
- Single Point of Contact (SPOC) service
- Minibus Schemes and Private Hire
- Ring and Ride Schemes
- Shopmobility
- Volunteers and Volunteering
- Wheels to Work

## **National Bus Pass**

Free bus passes may be available on all registered local bus services within England for eligible residents aged 60 years and over or those with disabilities.

**To obtain details contact your County Council, District Council or Unitary Authority.**

**Check your local taxi companies for purpose built wheelchair access taxis in Yellow Pages and Thompson Local Directory**

## **Mobility, Disability Aids, Independent Living Aids**

### **Shopmobility**

Shopmobility is a scheme which lends or hires mobility equipment to members of the public with limited mobility, to shop and to visit leisure and commercial facilities within the town or shopping centre:

- manual wheelchairs
- powered wheelchairs
- powered scooters

**For information contact Shopmobility**

**Check your local taxi companies for purpose built wheelchair access taxis in Yellow Pages and Thompson Local Directory**

### **British Red Cross**

British Red Cross offers the following medical equipment on loan:-

- Bathroom aids            Rivera and Bath-Wizard bath lifts and shower stools
- Daily living aids        Riser/recliner chairs, overbed tables, trolleys and stools
- Small aids                Including jar openers, tap turners, peelers and plug pullers
- Toilet aids                Commodes, toilet rails, raised toilet seats and grab rails
- Walking Aids             Rollators, tri-walkers, walking frames and walking sticks
- Wheelchairs

**For information contact British Red Cross**

**Telephone 0845 331 3331  
Delivery service 0845 331 3331  
[www.redcross.org.uk](http://www.redcross.org.uk)**

There are retail showrooms in the area that sell mobility and disability aids that will assist the cared for person in their day to day living.

The Independent Living Centre does not sell equipment, but offers professional and impartial advice on how to choose, where to buy and often an opportunity to try out equipment.

The aids available include:-

- Household items and kitchenware
- Pressure relief and positioning pillows and cushions
- Wheelchairs and walking aids
- Bathing and toileting aids including incontinence care
- Homecare
- Therapy
- Moving and Handling
- Orthopaedic

**For details contact your District Council or your Unitary Authority**

### **Personal Alarm Systems**

A Community Alarm is an easy to operate system in your home that connects the alarm base unit to an emergency response centre and can summon help immediately in an emergency.

An alarm button to summon help is located on the base unit.

A pendant can be worn around the neck or like a watch to summon help if you are away from the base unit, whether in the house or in the garden.

A Monitoring Alarm can be as simple as a baby alarm. More complicated alarms can be bought through a local equipment provider. Specialised alarms are available for people with sensory loss.

**Information about alarm systems can be obtained through your local Crime Prevention Officer, private companies, your County Council, District Council or Unitary Authority.**

### **Telecare**

A range of equipment can be added on to the basic community alarm system. Instead of relying on the client to press a button to summon help, sensors attached to pieces of equipment, for example, a movement sensor or a fall detector will automatically alert the centre when a client has left their home or had a fall. This then allows an appropriate response to be provided to the client, often by carers or relatives.

For environmental risks there are a range of detectors, such as smoke, carbon monoxide, natural gas and flood.

For personal risks there are devices which monitor movement, falls, imminent epileptic seizures, night time incontinence, bed or chair occupancy, medication, exiting property, bogus caller/panic buttons and visual alert door access.

**For details contact your District Council or your Unitary Authority**

### **Personal tracker system. Global Positioning System (GPS)**

If you are a carer / next of kin of someone with dementia, a personal tracker system Global Positioning System (GPS) can pinpoint and track a person's location should that the person become lost.

The GPS personal tracker is very useful in helping the emergency services, and you, to locate the cared for person very quickly. This gives peace of mind and helps to ensure their safety.

There are several GPS tracking systems available on the market and costs vary. It is therefore advisable to seek expert advice prior to purchase.

**To obtain information visit**

**GPS Personal Tracker Systems UK**

**Obtain information, factsheets and leaflets from:-**

<b>Age UK</b>	<b>National Telephone</b>	<b>020 8765 7200</b> <b><a href="http://www.age.org.uk">www.age.org.uk</a></b>
<b>Alzheimer's Society</b>	<b>National Telephone Dementia helpline</b>	<b>020 7423 3500</b> <b>0845 300 0336</b> <b><a href="http://www.alzheimers.org.uk/factsheets">www.alzheimers.org.uk/factsheets</a></b>
<b>Citizens Advice Bureau (CAB)</b>	<b>National Telephone Find a Bureau near you</b>	<b>03444 111 444</b> <b><a href="http://www.citizensadvice.org.uk">www.citizensadvice.org.uk</a></b>
<b>County Council, District Council or Unitary Authority</b>		

**For further details see Section 13 (Telephone numbers etc) & Section 14 (Factsheets etc).**

## Section 3: Carer Support

### Emergency Duty Team Carers support (Out of Hours)

**Obtain information about the emergency duty / out of hours social care team**  
**Contact your County Council, District Council or Unitary Authority.**

As carers we are all on a similar pathway. The support of other carers is very comforting as they know and understand how you are feeling, and the emotions you are experiencing. We can all feel anger, worry, sadness, guilt, loneliness, isolation, confusion, longing for the past, wanting to turn the clock back. Unfortunately this is not possible, we must live for today, tomorrow and the future.

Get to know your Dementia Support Worker or Dementia Advisor responsible for the cared for person. They will be able to help you get practical help in your caring role.

### Accepting help

It is not unknown for carers to refuse help in the early stages of an illness. It is vital to accept the help and support you will need as time progresses. By accepting help you will know that you are not alone. Your local Community Mental Health Service is a vital link where workers from a range of professional backgrounds will be able to help with practical problems and provide advice to people who use services and carers. Their role is to provide community interventions where practicable, to help people stay in their own homes.

### Support Services

#### Alzheimer's Society

Alzheimer's Society provides arrange of support services for people with dementia, their families and their carers in your area:-

- **Dementia Advisers** provide information and guidance to people with dementia and their carers from their dementia helpline
- **Dementia Support Workers** provide one to one information and practical support to people with dementia and their carers
- **Befriending** connects people with dementia with a trained volunteer to give them the opportunity to do more of the things they enjoy, either out in the community, or at home
- **Memory Matters Groups** offer support and education to people who have recently received a diagnosis of dementia. These groups are held in various locations
- **Memory Café** is a place for people with dementia and their carers to share information and experiences, or to simply have a cup of tea and chat.
- **Peer Support** groups for people with dementia or carers and families
- **Service User Review Panel** run by people with dementia to advise and feedback on local issues. These groups are held in various locations
- **Singing for the Brain** Is a stimulating group activity, for people in the early to moderate stages of dementia and their carers, which can help with general well being and confidence.

**For information, support and confidential guidance, speak to trained advisers on the Dementia Helpline**  
**Telephone 0845 300 0336**

## **Dementia Support Service**

Dementia Support Workers / Dementia Advisers can give you expert practical advice and support to help you understand dementia, cope with the day-to-day challenges it brings, and prepare for the future. This includes helping you access other support services, and build support networks within your community. The service helps you feel supported, maintain independence, choice and control over your life.

**For information about the support service or any questions about dementia contact:-  
Contact your County Council, District Council or Unitary Authority.**

## **Carers Groups**

Carers groups are run by doctor's surgeries, hospitals, clinics or by volunteer organisations. Speak to other carers in the group and on the telephone. Sharing your experiences helps you both through difficult times.

Have time for yourself by using the take a break scheme, day centre or have short break care for the cared for person, either in their own home, residential or nursing home.

**Ask at Doctor's surgeries, hospitals, clinics, day centres and other carers for details of local carers groups.**

## **Memory Cafés**

A Memory Café is a drop in centre, which is open on a regular basis to provide information for anyone who has, or is worried about, memory loss. People with dementia and their family or carers are encouraged to attend. Often a qualified health professional will be in attendance for confidential, private consultation. Memory Cafés provide information and peer support for you and the cared for person. They are run by a number of local agencies, including partnerships between the voluntary sector, the NHS and local Authorities.

**For details Visit**

**[www.memorycafes.org.uk](http://www.memorycafes.org.uk)**

## **Take a Break**

As a member of the 'Take a Break' scheme, which provides short breaks for carers in people's own homes, you will be allocated 3 hours per week of the take a break service. These hours can be saved and used in blocks of up to 12 hours at any one time. Vouchers are used to administer the scheme. Every three months you will receive 39 vouchers in the post. Each voucher is equivalent to a one hour break. There is a nominal charge for each 1 hour voucher used. The voucher is only valid for the current three month period.

**Details of Take a Break, scheme can be obtained from your County Council, District Council or Unitary Authority.**

## **Carer's Alert Card Scheme**

The Carer's Alert Card is designed to provide round the clock assistance to ensure that if the carers have an emergency, support is put in place to enable the cared for person to be looked after. The card only has a reference number on it. All personal details are held at a secure central data base.

The card is carried in your hand bag or wallet.

**Details of Carers Alert Card scheme can be obtained from your County Council, District Council or Unitary Authority.**

## **Flexible Break Grant**

The scheme is intended to be flexible and enable you to have a break that suites you. The grant can be used for holidays and trips, with or without the person you care for, personal development or the purchase of equipment to pursue hobbies and leisure activities.

**Details of Flexible Break grant scheme can be obtained from your County Council, District Council or Unitary Authority.**

### **Respite Care (Short breaks)**

Respite care gives people a chance to relax by having a break or taking a holiday. The care can be provided either at home or away from the home. Respite care is short-term care used as a temporary alternative to a person's usual care arrangements. It is important that carers have regular breaks and make time for their own needs. Respite care may also be needed in other situations, the carer might have to go into hospital or have other important commitments.

**Details of Respite Care scheme can be obtained from your County Council, District Council or Unitary Authority.**

### **Mentoring Service**

A Community Mentoring Service can offer support and help if you are experiencing difficulties because of isolation, stress, depression or anxiety. A local coordinator will get in touch and arrange to visit you to find out how a community mentor can help. The mentor can point you in the direction of other organisations able to help you, and plan what you would like to achieve with the help of the service. As well as being open to carers, this service is also provided for people in the early stages of dementia.

**Obtain information, factsheets and leaflets from:-**

<b>Age UK</b>	<b>National Telephone</b>	<b>03020 8765 7200</b> <b><a href="http://www.age.org.uk">www.age.org.uk</a></b>
<b>Alzheimer's Society</b>	<b>National Telephone Dementia helpline</b>	<b>020 7423 3500</b> <b>0845 300 0336</b> <b><a href="http://www.alzheimers.org.uk/factsheets">www.alzheimers.org.uk/factsheets</a></b>
<b>Citizens Advice Bureau (CAB)</b>	<b>National Telephone Find a Bureau near you</b>	<b>03444 111 444</b> <b><a href="http://www.citizensadvice.org.uk">www.citizensadvice.org.uk</a></b>
<b>County Council, District Council or Unitary Authority</b>		

**For further details see Section 13 (Telephone numbers etc) & Section 14 (Factsheets etc).**

## Section 4: Looking after Yourself

Part of doing your best is looking after yourself, making time to relax is very important. If you try to continue day after day without a break, you invite stress and depression. Even a short period away from the routine can work wonders.

It is important to look after yourself when you are caring for someone with dementia, it can be all too easy to ignore your own needs and to forget that you matter as well.

If there is a day centre or sitting service in your area that will allow you to get out for a while, use it. When you feel the need for a longer rest, ask your Care Manager about respite care and be insistent. Do not be afraid to approach your friends and family for support, your role as a carer is exhausting. You are entitled to expect help.

There may be a local self help group you can join, this is a good idea, sharing and discussing your problems. You can learn how others deal with difficulties similar to your own.

Laugh and try to retain a sense of humour. Laughing with the cared for person can help to relieve a stressful situation. Remember there are funny times. We can laugh at the funny times, we are not laughing at our loved ones we are laughing with them.

If the time comes when you can no longer cope, don't be too hard on yourself. If the cared for person needs to be admitted to hospital, or residential care, this is not a sign of failure on your part. It is often the best and safest solution for all concerned.

### Health matters

As a carer your health is important. If you become unwell and do not get help, you may be unable to continue looking after the person you care for. Take the time to consult your doctor about your own health. Simple treatments like having a 'Flu Jab', for example, could help you avoid illness.

Because of your caring role, do not ignore warning symptoms that might indicate a developing illness or a serious condition. Services can be put in place to support you even if you are compelled to have time away from your caring role.

### Carers Health and Wellbeing Checks

Carers often neglect their own health because they focus their attention on the needs of others. This can mean health problems that arise get worse or the carer does not pay enough attention to staying healthy. Health and Wellbeing checks are being offered to carers. These simple checks can highlight areas for support. They have been developed from what carers have told us are the important questions to consider.

For information contact **your local surgery**

### Safety in the home

Staying safe whilst caring for someone with dementia is exhausting and as their ability to reason declines, potential hazards increase.

Be aware of risks in the home such as gas appliances, trailing wires, electrical equipment, low glass tables, loose rugs, medicines and cleaning materials (bleach etc.)

Make sure the cared for person is kept away from anything that might harm them. Remember you cannot remove all hazards, but you can be vigilant and aware of new dangers that might develop. As long as you learn to look out for problems, you are doing all that can be expected.

## Care and Repair

Care and Repair services offer help to older people and those with disabilities of any age get repairs, improvements and alterations done for their home. Help to make people's homes warmer, safe, secure and more comfortable so that they can live at home for as long as they may wish to do so. Work with many other organisations in doing this, in particular to help them get the benefits and services that they may be entitled to.

**To obtain details contact your County Council, District Council or Unitary Authority.**

## Safe at home

Safe at Home is a free and friendly handyperson service for carers of people who are vulnerable due to age, disability or financial circumstances or who have been victims of crime.

Services provided are:-

- Visit and talk to you about your home
- Provide up to 2 hours free handyperson help
- Provide door or window locks and door chains
- Fit grab rails
- Help move small items of furniture
- Carry out small plumbing repairs
- Change light bulbs and install smoke alarms
- Fit key safes
- Secure loose floor coverings

**To obtain details contact your County Council, District Council or Unitary Authority.**

Your Fire and Rescue Service may carry out a free home safety visit for the occupier, providing advice and guidance on their fire and home safety needs and provide specialist alarms for people with hearing or sight impairment.

**To obtain details contact your County Fire and Rescue Service**

**If you have safety concerns about water, electricity, gas appliances or other risks, (e.g. gas or carbon monoxide leaks) contact your utility company immediately, as they are able to offer specialist advice and support to mitigate any risks.**

## Diet

It is important to do what you can to make sure that the cared for person and yourself enjoy their food and eat a healthy balanced diet. As dementia progresses eating can become difficult for some people. By making a few changes you can help keep mealtimes as enjoyable and stress free as possible. Sometimes a person with dementia may eat more food than they need. If they are eating excessive amounts, try to limit their food intake to prevent them eating too much and becoming overweight.

Contact your doctor if you have any specific concerns about nutrition or other problems associated with eating for either the cared for person or yourself. If appropriate a specialist such as a Dietician, Occupational Therapist or Speech and Language Therapist can help.



**Obtain information, factsheets and leaflets from:-**

<b>Age UK</b>	<b>National Telephone</b>	<b>03020 8765 7200</b> <b><a href="http://www.age.org.uk">www.age.org.uk</a></b>
<b>Alzheimer's Society</b>	<b>National Telephone Dementia helpline</b>	<b>020 7423 3500</b> <b>0845 300 0336</b> <b><a href="http://www.alzheimers.org.uk/factsheets">www.alzheimers.org.uk/factsheets</a></b>
<b>Citizens Advice Bureau (CAB)</b>	<b>National Telephone Find a Bureau near you</b>	<b>03444 111 444</b> <b><a href="http://www.citizensadvice.org.uk">www.citizensadvice.org.uk</a></b>
<b>County Council, District Council or Unitary Authority</b>		

**For further details see Section 13 (Telephone numbers etc) & Section 14 (Factsheets etc).**

## Section 5: Carers Rights and Assessments

### Who is a carer?

A carer is someone who helps another person, usually a relative or friend, in their day-to-day life. This is not the same as someone who provides care professionally, or through a voluntary organisation.

### Carer's Assessment

#### The Care Act 2014: The Law for carers

#### Assessments

The Act gives local authorities a responsibility to assess a carer's needs for support. These assessments are to be carried out regardless of the local authority's view of the level of those needs or of the person's financial resources. They aim to ensure the carers wellbeing. Carers' assessments must seek to establish not only the carer's needs for support, but the sustainability of the caring role itself, including such issues as the carer's potential future needs, their willingness to care, the impact of caring on other aspects of their lives. Local authority's must identify any children involved in the provision of care and where relevant, must consider whether to undertake a young carer's assessment or a child's assessment.

If both the carer and the person they care for agree, a combined assessment of both their needs can be undertaken.

#### Carer support planning.

The government have introduced national eligibility criteria for access to certain services. Where local authorities have determined that a person has any eligible needs, they **must** meet these needs, subject to meeting the financial criteria. Local authorities must take all reasonable steps to involve the people concerned and their representatives (or advocates) in preparing care and support plans. The carer and the local authority will agree a **Support Plan** setting out how the carer's needs may be met. This could include whether the carer wants to work, or continue to work, assistance with housework or help with technology so that a carer may keep in touch with family. Consideration of short break provision should also be made.

#### Charging and financial assessment

In most cases local authorities do not charge for providing support to carers, in recognition of the valuable contribution that carers make to their local community. However, this is something that the local authority can decide. If the local authority does decide to charge a carer for providing them with support, it must carry out a financial assessment to decide whether the carer can afford to pay. If supporting a carer involves providing care to the person being cared for, the local authority will charge for that care, but must carry out a financial assessment of the person who is being cared for. This is because the care would be provided directly to that adult, and not to the carer.

#### Personal budgets

Where a Support Plan is agreed, carers should be offered a personal budget, which is a statement showing the cost of meeting their needs, as part of their support plan. It will include the amount the carer will pay, if any, and the amount the local authority is going to pay. Carers have a right to request that the local authority meets some, or all of such needs by giving them a direct payment, which will give them control over how their support needs are arranged.

**To obtain details contact your County Council, District Council or Unitary Authority.**

## Advocacy

Advocacy is taking action to help people say what they want, secure their rights, represent their interests and obtain services they need.

Advocacy schemes work in partnership with the people they support and take their side.

Promotes social inclusion, equality and social justice

**To obtain details contact your County Council, District Council or Unitary Authority.**

## Hospital discharge

Hospital discharge is the term used when a person leaves hospital once they are sufficiently recovered. People with dementia usually need further long term help after leaving hospital. Some people with dementia move into a care home. Others need further long term help in their own home, or in the home of a relative or friend.

Before a person is discharged from hospital, their needs must be assessed by the multi disciplinary team so that any support or care services they need can be arranged before the person leaves hospital. Any organisations that will be providing these services must be made aware of when the person is due to be discharged.

The person leaving hospital should be fully involved in this assessment with input from family, carers and friends if deemed appropriate.

It may also involve the person's consultant, nursing and ward staff, physiotherapists, occupational therapists and social worker.

## Healthwatch

Healthwatch is your local champion for health and social care. They ensure that the voices of service users reach the ears of the decision makers, and are taken seriously.

- **People First.** The starting point is always the person with health and social needs.
- **Partnership.** Working with groups, seeking a stronger voice together.
- **Inclusion.** Having a particular responsibility for championing the needs of those are often not heard.
- **Critical Friendship.** Where service providers excel, it is recognised and celebrated. Where they are struggling, they receive advice and support. Where they are failing, they are told.
- **Focus.** Healthwatch cannot do everything, everywhere, all the time, but will choose the issues that matter most to the consumer and where a clear difference can be made

### Obtain information, factsheets and leaflets from:-

<b>Age UK</b>	<b>National Telephone</b>	<b>03020 8765 7200</b> <b><a href="http://www.age.org.uk">www.age.org.uk</a></b>
<b>Alzheimer's Society</b>	<b>National Telephone</b> <b>Dementia helpline</b>	<b>020 7423 3500</b> <b>0845 300 0336</b> <b><a href="http://www.alzheimers.org.uk/factsheets">www.alzheimers.org.uk/factsheets</a></b>
<b>Citizens Advice Bureau (CAB)</b>	<b>National Telephone</b> <b>Find a Bureau near you</b>	<b>03444 111 444</b> <b><a href="http://www.citizensadvice.org.uk">www.citizensadvice.org.uk</a></b>
<b>County Council, District Council or Unitary Authority</b>		

**For further details see Section 13 (Telephone numbers etc) & Section 14 (Factsheets etc).**

## Section 6: Carer Training

As a carer you need information to understand what causes dementia, also advice and support on problems facing the cared for person and the carer in the future. Carers training courses are designed to do this in a very informative and relaxed environment.

A carers training course is a source of valuable information for you now, and what you will encounter in the future.

On the training courses, as a group, carers are a great source of information, sharing their experiences with each other.

### Current topics include:-

- Basic first aid
- Behaviour problems
- Benefits and allowances
- Better Nutrition
- Communication strategies
- Coping with dementia
- Emergency first aid and patient handling
- Falls awareness for carers
- Managing incontinence
- Preventing falls
- Safe moving and handling
- Stress management
- What causes dementia
- What support is available for the cared for and carer

**IT IS NEVER TOO EARLY TO ATTEND  
A CARERS TRAINING COURSE**

**BOOK IT NOW**

Obtain information, factsheets and leaflets from:-		
<b>Age UK</b>	<b>National Telephone</b>	<b>03020 8765 7200</b> <b>www.age.org.uk</b>
<b>Alzheimer's Society</b>	<b>National Telephone</b> <b>Dementia helpline</b>	<b>020 7423 3500</b> <b>0845 300 0336</b> <b>www.alzheimers.org.uk/factsheets</b>
<b>Citizens Advice Bureau (CAB)</b>	<b>National Telephone</b> <b>Find a Bureau near you</b>	<b>03444 111 444</b> <b>www.citizensadvice.org.uk</b>
<b>County Council, District Council or Unitary Authority</b>		

For further details see Section 13 (Telephone numbers etc) & Section 14 (Factsheets etc).

## **Section 7: Financial and Legal Implications**

### **IT IS VERY IMPORTANT TO ARRANGE THE FINANCIAL AFFAIRS FOR THE CARED FOR PERSON AND YOURSELF BEFORE IT IS TOO LATE**

#### **Wills**

Everyone should make a Will. A Will ensures that when a person dies, their possessions and/or money go to the people of their choice. People with dementia who wish to make or change their Will should seek legal advice from a solicitor as soon as possible. This is because there may be issues about that person's mental capacity to understand and special arrangements may have to be made.

It is important that people make a Will safeguarding their family's financial interests.

#### **Setting up a Trust**

If the person with dementia has investments, property or savings, they can set up a Trust to ensure that these assets are managed in their chosen way. To do this the person must be able to convey their wishes clearly. A Trust is a very powerful legal document giving a nominated person authority to deal with your financial affairs. It is wise to take advice from your solicitor on your choice of Attorney(s) to ensure that they act on your behalf and in your best interests. You can also in a similar way appoint someone to make decisions about health and personal welfare. People may wish to set up a Trust safeguarding their family's financial interests.

#### **Enduring Power of Attorney (EPA)**

Before October 2007 people could grant an Enduring Power of Attorney (EPA) to one or more trusted person(s) attorney(s), provided that both the donor of the power and the attorney(s) signed the document prior to 1<sup>st</sup> October 2007. Any EPA remains valid whether or not it has been registered at the Court of Protection. An EPA can be used while you still have mental capacity, provided you consent to its use. If you start to lose the mental capacity to manage your finances, your attorney(s) are under a duty (under certain circumstances) to register your EPA with the Office of the Public Guardian (OPG).

#### **Lasting Power of Attorney (LPA), Property and Affairs**

Anyone who has been diagnosed with dementia, who has not made a Property and Affairs LPA, who owns property, investments or has an income other than benefits, should make one. An LPA gives the attorney(s) the legal right to act on a person's behalf when they are no longer able to act for themselves. It is a very powerful legal document giving that person(s) absolute control over all your financial affairs. It is in your best interest to appoint two people plus your solicitor to act on your behalf as attorney(s). It can only be used once it has been registered at the Office of the Public Guardian (OPG).

#### **Lasting Power of Attorney (LPA) Personal Welfare**

Anyone who is worried that they may develop dementia in the future, or has been diagnosed with dementia and is concerned about how decisions regarding their medical treatment might be made, should they lose the ability to decide for themselves, should consider making a Personal Welfare LPA. They may fear that life sustaining or life-prolonging treatments would be provided long after they were able to achieve a level of recovery, length of life or quality of life that the person would at present consider to be acceptable or tolerable.

Because a Personal Welfare LPA (advance decision/living will) concerns health care, you should consult your General Practitioner (GP) and solicitor before drafting and signing.

Once enacted, your chosen attorney(s) are allowed to make decisions about your personal welfare. It can only be used after it has been registered at the Office of the Public Guardian (OPG) and you have become mentally incapable of making decisions about your own welfare.

## **Court of Protection**

The Court of Protection is a Court which can direct how a person's finances should be dealt with if there are issues about mental capacity. The Court acts under very strict rules. It has wide powers which can sometimes prove restrictive for those appointed by them to act for a person who has lost capacity to deal with their financial affairs. If no EPA or LPA exists the Court of Protection is a last resort having the power to appoint a deputy to act on the cared for persons financial behalf. It can divide joint bank accounts causing great inconvenience to other persons. There is an initial charge, plus a yearly charge to audit the accounts. Every penny received and paid out must be accounted for, backed up by receipts.

It is very important and advantageous to have people's affairs in order well before this stage.

## **The Mental Health Act 2007**

The Mental Health Act 2007 replaces the Mental Act 1983. The sections of the 1983 act which are relevant to people with dementia and their carers remain largely unchanged. The Mental health Act 2007 deals with people who are medically assessed as having a 'mental disorder'. If a person is thought to be at risk to themselves or to others, or if it is felt that their health is at risk, they can be detained in hospital under this act. This is commonly known as 'being sectioned' under the act. Most people are, however, admitted into hospital on a voluntary basis.

## **Mental Capacity Act 2005**

The Mental Capacity Act 2005 provides a statutory framework to empower and protect people who are aged 16 and over who lack, or may lack, capacity to make certain decisions for themselves because of illness, a learning disability, or mental health problem.

The main purpose of the act is to clarify and reform the current common law provisions which govern the ways in which people can and should deal with those people who lack decision making capacity. It is supplemented by new statutory schemes for advanced decision making and court-based resolution of disputes or difficulties. The act covers decisions relating to an individual's property and financial affairs, together with decisions regarding health care treatment and more everyday decisions such as personal care.

## **Deprivation of Liberty (DOL) Safeguards 2009**

As part of the Mental Capacity Act, DOL Safeguards are now in place for people in hospitals and care homes who lack capacity or who can't make their own decisions about their care.

A DOL authorisation must be obtained where people need to have their liberty taken away from them in order to receive care and/or treatment that is in their best interests and that protects them from harm. It is the responsibility of the local Primary Care Trust (for hospitals) or Local Authority (for care homes) to ensure appropriate assessments and reviews are in place.

## **Financial advice**

To make the best use of Trusts, Wills and Investment Planning including Powers of Attorney it may be useful to ask a professional to assist in collating and advising in all the financial aspects and implications.

Organisations such as banks operate 'in house' advice teams which frequently change and which are typically restricted to offering advice only on the bank's own products.

Independent Financial Advisors, registered by the Financial Services Authority, can offer independent advice on the best way to safeguard a person's financial aspects when faced with a dementia driven situation.

Independent Financial Advisors are usually localised businesses offering personal continuity and are able to provide advice from the whole of the financial market.

Independent wide ranging financial advice would be tailored to assist close family members/carers through an extremely difficult period and may be a prompt to put similar safeguards in place to possibly assist their own children in years to come.

**Obtain information, factsheets and leaflets from:-**

<b>Age UK</b>	<b>National Telephone</b>	<b>03020 8765 7200</b> <b>www.age.org.uk</b>
<b>Alzheimer's Society</b>	<b>National Telephone</b> <b>Dementia helpline</b>	<b>020 7423 3500</b> <b>0845 300 0336</b> <b>www.alzheimers.org.uk/factsheets</b>
<b>Citizens Advice Bureau (CAB)</b>	<b>National Telephone</b> <b>Find a Bureau near you</b>	<b>03444 111 444</b> <b>www.citizensadvice.org.uk</b>
<b>County Council, District Council or Unitary Authority</b>		

**For further details see Section 13 (Telephone numbers etc) & Section 14 (Factsheets etc).**

## Section 8: Benefits

### **CHECK THAT ALL BENEFITS ARE BEING CLAIMED. IT IS MOST IMPORTANT YOU ARE BOTH ASSESSED FOR BENEFIT ENTITLEMENTS NOW**

The cared for person and the carer need to be assessed for any benefits they are entitled to receive. Take advice on all the financial aspects of this step.

The benefits system is complicated and finding out to what you are entitled can be difficult. Claiming benefits usually involves filling out forms but do not let this put you off. It is vital to get the right advice about any welfare benefits to which the cared for and the carer may be entitled. Some benefits are not means tested.

There are a range of agencies that may be able to help you.

**Phone the Pensions Office (Benefits Agency) for a personal appointment to see a customer liaison manager for assistance to fill in claim forms at home.**

Possible benefits to claim (in alphabetical order) are:

- Attendance allowance
- Bereavement benefit
- Carer's allowance
- Council tax benefit
- Direct payments
- Disability living allowance
- Employment Support Allowance (formally Incapacity benefit)
- Housing benefit
- Pension credit
- Retirement pension
- Severe disablement allowance
- Warm front grants
- Widow's benefit
- Winter fuel payment

### **Benefit checks**

Several organizations offer free confidential, impartial and independent advice at local drop in centres. Providing information on benefits entitlement, advocacy and support to claimants, assisting them to maximize benefit income. Help with form filling. A home visiting service is available.

### **Appointee**

When the cared for person eventually becomes unable to manage their income, someone will need to be appointed, known as an appointee, to administer their income in the cared for person's best interest. The appointee should ensure that all income is claimed, including all benefits where appropriate and all every day living expenses are paid.

When the cared for person with dementia eventually becomes unable to manage the income from their benefits someone will need to be appointed, known as an appointee, to administer this income in the cared for person's best interest. Ensuring that all benefits are claimed and to pay every day living expenses.

Wherever possible, the appointee should be a close relative who either lives with the person with dementia or visits them frequently. In certain circumstances the appointee might be a friend, neighbour or caring professional, it must be someone who can be trusted. Sometimes it is better to have a formal appointment depending on the individual circumstances under a Lasting Power of Attorney or through the Court of Protection.



You can only be an appointee if a court of law or a government department has appointed you to act on someone else's behalf.

You are an appointee if you have been appointed to act for the cared for person "called a claimant" by one or more of the following:

- The Department for Works and Pensions (DWP)
- HM Revenue and Customs (HRMC)
- The Department for Social Development (DSD) in Northern Ireland
- A court of law

**Obtain information, factsheets and leaflets from:-**

<b>Age UK</b>	<b>National Telephone</b>	<b>03020 8765 7200</b> <b><a href="http://www.age.org.uk">www.age.org.uk</a></b>
<b>Alzheimer's Society</b>	<b>National Telephone Dementia helpline</b>	<b>020 7423 3500</b> <b>0845 300 0336</b> <b><a href="http://www.alzheimers.org.uk/factsheets">www.alzheimers.org.uk/factsheets</a></b>
<b>Citizens Advice Bureau (CAB)</b>	<b>National Telephone Find a Bureau near you</b>	<b>03444 111 444</b> <b><a href="http://www.citizensadvice.org.uk">www.citizensadvice.org.uk</a></b>
<b>County Council, District Council or Unitary Authority</b>		

**For further details see Section 13 (Telephone numbers etc) & Section 14 (Factsheets etc).**

## Section 9: Understanding Domiciliary Care

Domiciliary Care, sometimes known as home help or home care, covers a number of different services available to the cared for person in their own home, and is provided so they remain as independent as possible. Domiciliary care agencies providing personal care to people in their own homes have to be registered by the Care Quality Commission (CQC), the same organisation that regulates care homes.

You may need help for a short time until you can manage for yourself, or sometimes on a more permanent basis. In most cases the person wants to stay in their own home, and the service aims to help them to do just that.

Adult and Community Services will carry out an assessment of the needs of the cared for person. This help could involve washing and dressing in the mornings, undressing and helping to bed, in the evenings, supervising the administration of medication and preparation of meals. They will also be financially assessed to see if they will need to make a financial contribution towards the cost of any services.

Domiciliary care can be arranged by contacting your social worker or Key Worker/Care Manager. This service is provided by a private company and funded by social services within certain financial guide lines.

**To obtain details contact your County Council, District Council or Unitary Authority.**

### Direct payments

These are payments made to individuals by Adult and Community services to enable the cared for person to buy assessed services and provide money to pay for social care services. This gives the cared for person greater choice and control over their lives. It enables them to make their own decisions about how their care is delivered. Payments can be used for

- Companionship Services
- Home help services
- Personal care services

You can also receive direct payments if you are a carer who has been assessed as needing support in your own right.

### Obtain information, factsheets and leaflets from:-

<b>Age UK</b>	<b>National Telephone</b>	<b>03020 8765 7200</b> <b><a href="http://www.age.org.uk">www.age.org.uk</a></b>
<b>Alzheimer's Society</b>	<b>National Telephone Dementia helpline</b>	<b>020 7423 3500</b> <b>0845 300 0336</b> <b><a href="http://www.alzheimers.org.uk/factsheets">www.alzheimers.org.uk/factsheets</a></b>
<b>Citizens Advice Bureau (CAB)</b>	<b>National Telephone Find a Bureau near you</b>	<b>03444 111 444</b> <b><a href="http://www.citizensadvice.org.uk">www.citizensadvice.org.uk</a></b>
<b>County Council, District Council or Unitary Authority</b>		

**For further details see Section 13 (Telephone numbers etc) & Section 14 (Factsheets etc).**

## Section 10: Understanding Residential Care

Some carers decide that, come what may, they will try to continue looking after the cared for person in the home environment. It is not unknown for substantial support packages to be put into place and even 'continuing care' to be awarded in these cases. Remember, to keep the cared for person at home is your choice.

In many carers lives however, there comes a time when they realise that, despite how hard they try, looking after a cared for person at home is no longer an option. Sometimes this point is reached after the carers themselves have been ill or after a period when the cared for person has been either in hospital or intermediate care. At this point there may have been a deterioration in the health, mobility or skills of the cared for person making caring in the home environment almost impracticable.

If this point has been reached the cared for person will be assessed by a professional health worker and advice given on the type of care home that should be chosen. This will largely depend upon the health and / or the behavioural traits of the cared for person.

To place the cared for person, into a home might be very difficult. One cannot prepare for the feelings of loss, failure, guilt, and lack of purpose that may come flooding to the surface. Many carers find this step to be the most painful and difficult to take.

Take heart however, many also find that once the cared for person is settled visiting often achieves quality time together without the daily work associated with caring.

### Residential Care Home

Provides support as if you are in your own home, and help with personal care such as getting up and going to bed, washing, dressing and going to the toilet.

### Nursing Care Home

Provides care for people with complex needs who require the skills of a qualified nurse. They are required by law to have a qualified nurse on duty 24 hours a day.

### Nursing Care Home (EMI / EMD registered)

For cared for persons who are very ill a category of nursing home exists which will have the necessary skills of qualified nursing staff but additionally have the skills to cope with more challenging behaviours.

These are known as nursing homes for the Elderly Mentally Infirm (EMI) or Elderly Mentally Disordered (EMD).

Your Care Manager / Key Worker will have a list of care homes that are approved by the local health authority and will assist you in this step. Take advice on the care homes and visit as many as you wish before choosing one.

To be registered all care homes have to be inspected by the Care Quality Commission (CQC) and if you have access to the internet you will be able to find the latest inspection reports for any particular care home.

As the carer you become the voice of the cared for person so you should be happy that the home you choose is the one that you feel most comfortable and safe with and that it is the best option for the cared for person.

Do not be pushed or bullied into a decision before you understand all the financial implications of the move.

Take advice on all the financial aspects of this step, with your local Financial Assessment and Benefit (FAB) team. Ask to be assessed for continuing care if the cared for person is very ill. This is where your record of medical treatment and Incidents will serve you well.

Choose the care home very carefully. Make sure it meets the cared for persons needs. The home should aim to give the cared for person as much choice and independence as possible. Ask about the room. Is it single, shared or en suite? Does the home provide varied meals, allow pets, telephone in room, arrange trips out, your own doctor, religious worship, activities and entertainment? Ask about their attitude towards the use of drugs.

Most care homes produce a brochure. This will tell you what services are available, and if the cared for person will have to pay for them out of their personal allowances.

### **Key Care Solutions**

Is a website which lists care & nursing homes and day care centres that have current vacancies. The simple and user friendly search facility is free to the public and enables you to search for care homes which specialise in dementia care. Many of the featured homes also accommodate day and short term respite care.

**For information contact Key Care Solutions**

**Telephone 0800 772 0123**  
**[www.keycaresolutions.co.uk](http://www.keycaresolutions.co.uk)**

### **Right Care index**

Right Care Index has a comprehensive list all the Care homes in Devon

**For information contact Right Care Index**

**Telephone 01872 321327**  
**[www.rightcareindex.com](http://www.rightcareindex.com)**  
**Email: [mail@rightcareindex.com](mailto:mail@rightcareindex.com)**

### **Obtain information, factsheets and leaflets from:-**

<b>Age UK</b>	<b>National Telephone</b>	<b>03020 8765 7200</b> <b><a href="http://www.age.org.uk">www.age.org.uk</a></b>
<b>Alzheimer's Society</b>	<b>National Telephone Dementia helpline</b>	<b>020 7423 3500</b> <b>0845 300 0336</b> <b><a href="http://www.alzheimers.org.uk/factsheets">www.alzheimers.org.uk/factsheets</a></b>
<b>Citizens Advice Bureau (CAB)</b>	<b>National Telephone Find a Bureau near you</b>	<b>03444 111 444</b> <b><a href="http://www.citizensadvice.org.uk">www.citizensadvice.org.uk</a></b>
<b>County Council, District Council or Unitary Authority</b>		

**For further details see Section 13 (Telephone numbers etc) & Section 14 (Factsheets etc).**

## Section 11: Counselling

When someone close to you has developed dementia you are likely to experience feelings of grief and bereavement, not only in the period after their death, but also as the illness progresses before they die. It may help to know that such feelings are normal and that other people experience similar reactions.

Carers groups are a great source of comfort. Other carers understand how you feel as they are going through or have been through the same emotions as you.

Knowing what to expect when someone nears the end of life is vitally important, both for the person who is ill and for their family and friends. Nothing can heal the deep feelings of pain and loss.

Having information can help us to prepare for the physical and emotional changes that we might be experiencing.

The following organizations can supply information and support you will find very useful:

### **Age UK Ltd.**

Offer free advice and support in times of bereavement.

**For information contact AGE UK Ltd**

**Telephone 0845 2967810**

[www.age.org.uk](http://www.age.org.uk)

### **Alzheimer's Society**

Supply factsheets, books, information and support through local branches of the society.

**For information contact Alzheimer's Society**

**Telephone 01392 368885**

[www.alzheimers.org.uk/factsheets](http://www.alzheimers.org.uk/factsheets)

### **Citizens Advice Bureau (CAB)**

Help people resolve their money, benefits, legal and other problems in times of bereavement by providing free advice and information.

**For information contact Citizens Advice Bureau**

**Telephone 01392 201210**

[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

### **Cruse Bereavement Care**

Provides help support, advice, counselling and information on practical matters at local branches to anyone who has been bereaved.

**For information and support contact Cruse**

**Telephone 0844 477 9400**

[www.crusebereavment.co.uk](http://www.crusebereavment.co.uk)

### **Samaritans**

Are people from all walks of life who offer a sympathetic listening ear, provide confidential and emotional support to anyone of any age who is going through a crisis. The Samaritans are available 24 hours a day, 365 days a year (calls charged at local rate).

**For information and support contact Samaritans**

**Telephone 08457 909 090**

[www.samaritans.org.uk](http://www.samaritans.org.uk)

### **The Silver Line**

is the only free confidential helpline open 24 hours a day, every day of the year.

Provides information, friendship and advice to older people, link callers to local groups and offers regular befriending calls.

**For information contact The Silver Line**

**Telephone 0800 4 70 80 90**

[www.thesilverline.org.uk](http://www.thesilverline.org.uk)

## End of Life

### Palliative care

Palliative care services are intended to keep the person as comfortable as possible and to ensure that they have the best quality of life. The service offers supportive care and help to the person and their family to enable them to cope as well as possible with the effects of the illness. Ask your Dementia Advisor / Dementia Support Worker if this service is available in your area

#### Obtain information, factsheets and leaflets from:-

<b>Age UK</b>	<b>National Telephone</b>	<b>03020 8765 7200</b> <b><a href="http://www.age.org.uk">www.age.org.uk</a></b>
<b>Alzheimer's Society</b>	<b>National Telephone</b> <b>Dementia helpline</b>	<b>020 7423 3500</b> <b>0845 300 0336</b> <b><a href="http://www.alzheimers.org.uk/factsheets">www.alzheimers.org.uk/factsheets</a></b>
<b>Citizens Advice Bureau (CAB)</b>	<b>National Telephone</b> <b>Find a Bureau near you</b>	<b>03444 111 444</b> <b><a href="http://www.citizensadvice.org.uk">www.citizensadvice.org.uk</a></b>
<b>County Council, District Council or Unitary Authority</b>		

For further details see Section 13 (Telephone numbers etc) & Section 14 (Factsheets etc).

## Section 12: Glossary

### Medical glossary of terms and abbreviations

ACUTE UNIT	A mental health hospital unit for people who have emergency, severe and/or challenging needs that requires treatment that cannot be provided in a less intensive local setting
AMHP (Previously known as ASW)	Approved Mental Health Practitioner
CAMCOG	Cambridge Cognitive Assessment
CAW	Community Assessment Worker
CAP	Community Alternative Programme
CARE MANAGER	Usually a social worker to oversee funding of the patient
CCT	Complex Care Team
CT or CAT SCAN	Computerised Axial Tomography
CJD	Creutzfeldt-Jakob disease
CMHS (OP)	Community Mental Health Services for Older People
CMHT	Community Mental Health Team
CMO	Community Medical Officer
CONSULTANT	Psychiatrist-in-charge
CPA	Care Programme Approach, agreeing an individualised care plan (You might hear this called a person centred plan)
CPN	Community Psychiatric Nurse
CSW	Carer Support Worker
CTG	Cardiotocography
DAY TREATMENT UNIT	Acts as a day treatment hospital and out patient department
DLB	Dementia with Lewy Bodies
ECG	Electro Cardiograph
ECR	Extra Contractual Referral is the term used for referring a patient to a specialist centre in another area
ECT	Electro Convulsive Therapy
EMD	Elderly Mental Disorder
EMI	Elderly Mentally Infirm
GP	General Practitioner (Family Doctor)
ICT	Intensive Community Treatment
KEY WORKER	Care co-ordinator. Could be GP, OT or CPN
MCI	Mild Cognitive Impairment
MDF	Manic Depression Fellowship
MDT	Multi Disciplinary Team
MIND	National Mental Health Charity
MMSE	Mini Mental State Examination
MND	Motor Neurone Disease
MRI SCAN	Magnetic Resonance Imaging
MS	Multiple Sclerosis
MSA	Multiple System Atrophy
NSF (1)	National Schizophrenia Fellowship
NSF (2)	National Service Framework
NHS	National Health Service
OCD	Obsessional Compulsive Disorder
OT	Occupational Therapist
PALS	Patient Advice & Liaison Service
PCT	Primary Care Trust
PD	Parkinsons Disease

PET SCAN	Position Emission Tomography
PICU	Psychiatric Intensive Care Unit
PSP	Progressive Supranuclear Palsy
PTSS	Post Traumatic Stress Syndrome
RMN	Registered Mental Health Nurse
RMO	Responsible Medical Officer (usually the consultant)
SANE	Mental health charity
SAP	Single Assessment Process
SHO	Senior House Officer (Hospital Doctor)
SOAD	Second Opinion Appointed Doctor, from the Mental Health Commission
SPECT SCAN	Single Photon Emission Computerised Tomography
SW	Social Worker
UNIT	Ward or outpatient facility

If any of the definitions are unclear to you, please discuss them with a medical professional.

### Non medical glossary of terms and abbreviations

AA	Attendance Allowance
ADW	Advanced Decision Will. (Formerly called a Living Will)
BEL	Benefits Enquiry Line
CAB	Citizens Advice Bureau
CDP	Care Direct Plus
CQC	Care Quality Commission
CRUSE	National Charity for Bereavement
DOL	Deprivation of Liberty
DFG	Disabled Facilities Grant
DLA	Disability Living Allowance
DCP	Dementia Carers' Pathways
DSD	Department for Social Development in Northern Ireland
DVLA	Driver and Vehicle Licensing Agency
DWP	Department for Works and Pensions
EPA	Enduring Powers of Attorney
FAB	Financial Assessment and Benefits Team
ICE	In Case of Emergency
ICAS	Independent Complaints Advocacy Service
LPA	Lasting Powers of Attorney
HMRC	HM Revenue & Customs
OPG	Office of the Public Guardian
REPoD	Rotarians Easing Problems of Dementia
SAP	Single Assessment Process



## Section 13: Telephone Numbers, Websites and Emails

Name	Telephone number / Website / Email Address
Action on Hearing Loss Formally Royal National Institute for the Deaf	Freephone 0808 808 0123
Age UK	Freephone National 0800 1696565 020 8765 7200 www.age.org.uk
<b>Alarm Systems</b>	
Age Concern (Aid Call)	Freephone 0800 7722 661
Saga	Freephone 0800 068 5059 www.saga.co.uk/sos
Alzheimer's Research UK	0300 111 5555 enquires@alzheimersresearchuk.org alzheimersresearchuk.org
Alzheimer's Society	National Dementia helpline 020 7423 3500 0845 300 0336 www.alzheimers.org.uk/factsheets
<b>Benefits</b>	
Pensions Office (Benefits Agency)	Enquiry line Pension services 0800 88 22 00 0845 6060 265 www.pensionsadvisoryservice.org.uk
British Red Cross	Delivery service 0845 331 3331 Delivery Service 0845 331 3331 www.redcross.org.uk
Care Quality Commission (CQC)	03000 616 161 www.cqc.org.uk
<b>Carer Support Groups</b>	
County Council, District Council or Unitary Authority	
Doctors Surgery	
Carers Direct	0300 103 1053 www.nhs.uk/carersdirect
Carers U K	National helpline free phone 0808 808 7777 01392 824752 www.carersuk.org Email adviceline@carersuk.org
Citizens Advice Bureaux (CAB)	National 03444 111 444 www.citizensadvice.org.uk
Cruse	0844 477 9400 www.crusebereavment.co.uk Email helpline@cruse.org.uk

## Community Transport

<b>County Council, District Council or Unitary Authority</b>	
<b>Dementia UK</b>	<b>Help line</b> 020 7874 7200 0845 257 0406 <a href="http://www.dementiauk.org">www.dementiauk.org</a> <b>Email</b> <a href="mailto:info@dementiauk.org">info@dementiauk.org</a>
<b>Department of Health</b>	0870 600 55 22 <a href="http://www.dh.gov.uk">www.dh.gov.uk</a>
<b>Disability Information Service</b>	0845 1551 005
<b>Emergency Ambulance, Fire, NHS Police Telephone Numbers</b>	
<b>Ambulance</b>	999
<b>Fire</b>	999
<b>NHS Help Line</b>	111
<b>Police</b>	999
	<b>Non Emergency</b> 101
<b>Healthwatch</b>	0800 520 640 <a href="http://www.healthwatch.co.uk">www.healthwatch.co.uk</a>
<b>H.M. Revenue and Customs (VAT)</b>	<b>Help line</b> 0845 010 9000 <a href="http://www.hmrc.gov.uk">www.hmrc.gov.uk</a>
<b>Key Care Solutions</b> Free search facility for finding the right care home or day centre	<b>Freephone</b> 0800 772 0123 <a href="http://www.keycaresolutions.co.uk">www.keycaresolutions.co.uk</a> <b>Email</b> <a href="mailto:info@keycaresolutions.co.uk">info@keycaresolutions.co.uk</a>
<b>Mencap</b>	0808 808 1111 / 0207 4540454
<b>Message in a bottle</b>	
<b>Loins Club</b>	0845 8339502 <a href="http://www.lionsclub.org.uk">www.lionsclub.org.uk</a> <a href="mailto:dchq@lions.org.uk">dchq@lions.org.uk</a>
<b>MIND (National Association for Mental Health)</b>	020 8519 2122 <a href="http://www.mind.org.uk">www.mind.org.uk</a>
<b>NHS Direct</b>	0845 46 47
<b>Multiple Systems Atrophy</b>	020 79404666 <a href="http://www.msatrust.org.uk">www.msatrust.org.uk</a> <a href="mailto:hello@msalocalhub.org.uk">hello@msalocalhub.org.uk</a>
<b>Office of the Public Guardian</b>	0300 456 0300 <a href="http://www.publicguardian.gov.uk">www.publicguardian.gov.uk</a>
<b>Parkinson's Disease Society</b>	0808 800 0303

<b>Pensions Office Benefits Agency</b>	<b>Freephone</b>	<b>0800 882 200 0845 606 0265 www.thepensionservice.gov.uk</b>
--	------------------	--

<b>Princess Royal Trust For Carers</b>		<b>0844 800 4361</b>
--	--	----------------------

### Publications

<b>Who Cares? Department of Health publication department</b>		<b>0300 1231 002 www.orderlinedh.gov.uk</b>
---	--	---

<b>Right Care Index A comprehensive health and social care directory</b>		<b>01872 321327 www.rightcareindex.com mail@rightcareindex.com</b>
--	--	--

<b>Still Going Strong. The Mental Health Foundation publication department Email</b>		<b>0207 8031 100 / 08457 909 090 mhf@mhf.org.uk</b>
--	--	---

### Radar key

<b>Royal Association for Disability and Rehabilitation (RADAR)</b>		<b>020 7250 3222 www.radar.org.uk</b>
--	--	---

<b>Rotarians Easing Problems of Dementia (REPoD)</b>		<b>01822 852102 www.repod.org.uk</b>
--	--	--

<b>Royal National Institute for the Deaf now Action on Hearing Loss</b>		<b>0808 808 0123</b>
---	--	----------------------

<b>Royal National Institute for the Blind</b>		<b>08457 669 999</b>
---	--	----------------------

<b>Samaritans</b>		<b>08457 909 090 www.samaritans.org.uk</b>
-------------------	--	--

<b>Saneline</b>		<b>08457 678 000</b>
-----------------	--	----------------------

<b>Shopmobility</b>	<b>National</b>	<b>0844 41 41 850 www.shopmobility.org</b>
---------------------	-----------------	--

<b>Stroke Association</b>	<b>National Help line Email</b>	<b>0845 3033 100 www.stroke.org.uk Info@stroke.org.uk</b>
---------------------------	-------------------------------------	---

<b>The Silver Line</b>	<b>Freephone</b>	<b>0800 470 80 90 www.thesilverline.org.uk</b>
------------------------	------------------	--

### Singing for the Brain

<b>Alzheimer's Society</b>	<b>National</b>	<b>020 7423 3500</b>
----------------------------	-----------------	----------------------

<b>Wand (Mental Health Helpline)</b>		<b>0808 800 0312</b>
--------------------------------------	--	----------------------

--	--	--

--	--	--

--	--	--

--	--	--

## Section 14: Factsheets and Leaflets

### Your County Council, District Council or Unitary Authority

#### Age UK factsheets

Have a wide range of factsheets which can be obtained from:-

Telephone 020 87657200  
[www.age.org.uk/factsheets](http://www.age.org.uk/factsheets)

#### Citizens Advice Bureaux (CAB) factsheets

Have a wide range of factsheets which can be obtained from:-

Telephone 03444 111 444  
[www.citizensadvice.org.uk/factsheets](http://www.citizensadvice.org.uk/factsheets)

#### Alzheimer's Society factsheets

Have a wide range of factsheets which can be obtained from:-

Telephone 020 7423 3500  
[www.alzheimers.org.uk/factsheets](http://www.alzheimers.org.uk/factsheets)

### Causes of dementia, progression and drug treatments

400	What is dementia?
401	What is Alzheimer's disease?
402	What is vascular dementia?
403	What is dementia with Lewy bodies?
404	What is Fronto-temporal dementia (including Pick's disease)?
405	Genetics and dementia
407	Drug treatments for Alzheimer's disease
408	Drugs used to relieve behavioural and psychological symptoms in dementia
417	The later stages of dementia
427	What is Creutzfeldt-Jakob disease (CJD)?
430	Learning disabilities and dementia
434	Complementary and alternative therapies
438	What is Korsakoff's syndrome?
440	Younger people with dementia
442	Rarer causes of dementia
444	Depression and anxiety
450	Am I at risk of developing dementia?
456	Dementia and the brain
458	The progression of Alzheimer's disease and other dementias
470	Mild cognitive impairment
527	Sight, perception and hallucinations in dementia

### Emotional and practical support

429	Equipment, adaptations and improvements and to the home
437	Assistive technology – devices to help with everyday living
439	Driving and dementia
445	Talking therapies (including counselling, psychotherapy and CBT)
448	Dental care and oral health
462	Replacement care (respite care) in England
471	After a diagnosis
474	Travelling and going on holiday
476	Selecting a care home
480	Supporting lesbian, gay and bisexual people with dementia
482	Moving into a care home – advice for lesbian, gay and bisexual people
484	Making decisions and managing difficult situations
500	Communicating

501	Walking about
502	Managing toilet problems and incontinence
503	Safety in the home
504	Washing and bathing
507	Grief, loss and bereavement
509	Dementia and aggressive behaviour
510	Dressing
511	Eating and drinking
512	Pressure ulcers (bed sores)
514	Sex and dementia
515	Explaining dementia to children and young people
516	Dealing with guilt
521	Staying involved and active
522	Staying healthy
523	Carers: looking after yourself
524	Understanding and respecting the person with dementia
525	Changes in behaviour
526	Coping with memory loss
528	Urinary tract infection (UTI) and dementia
529	Exercise and physical activity
531	End- of-life care

#### Health and social care

418	Assessment for care and support in England
425	How the GP can support a person with dementia
426	Diagnosis and assessment
452	Assessments for NHS-funded nursing care
453	Hospital discharge
454	How health and social care professionals can help
477	Care on a hospital ward

#### Legal and financial information

413	Benefits
414	Council tax
431	Benefit rates and income/savings thresholds
459	The Mental Health Act 1983 and Guardianship
460	Mental Capacity Act 2005
463	Advance decisions and advance statements
467	Financial and legal affairs
NI467	Financial and legal tips
472	Lasting powers of attorney
NI472	Enduring Power of Attorney and controllership
473	Personal payments
483	Deprivation of Liberty Safeguards
530	Becoming a deputy for a person with dementia
532	Paying for care and support in England
NI469	When does the health and social care trust pay for care?

#### Legal and financial information

413	Benefits
414	Council tax
431	Benefit rates and income/savings thresholds
NI431	Direct payments
459	The Mental Health Act 1983 and Guardianship

<u>460</u>	<u>Mental Capacity Act 2005</u>
<u>463</u>	<u>Advance decisions and advance statements</u>
<u>467</u>	<u>Financial and legal affairs</u>
<u>472</u>	<u>Lasting powers of attorney</u>
<u>473</u>	<u>Direct payments</u>
<u>483</u>	<u>Deprivation of Liberty Safeguards</u>
<u>530</u>	<u>Becoming a deputy for a person with dementia</u>
<u>532</u>	<u>Paying for care</u>

## Appendix i: Emergency details of cared for person

<b>NAME</b>	
<b>ADDRESS</b>	
<b>POST CODE</b>	
<b>TELEPHONE NUMBER</b>	

### EMERGENCY CONTACT DETAILS OF THE CARED FOR PERSON

<b>NAME</b>		<b>NAME</b>	
<b>RELATIONSHIP</b>		<b>RELATIONSHIP</b>	
<b>TELEPHONE NUMBER</b>		<b>TELEPHONE NUMBER</b>	
<b>HOME</b>		<b>HOME</b>	
<b>WORK</b>		<b>WORK</b>	
<b>MOBILE</b>		<b>MOBILE</b>	
<b>DOCTOR</b>		<b>SURGERY NAME</b>	
<b>TELEPHONE</b>		<b>OUT of HOURS</b>	

### LIST OF MEDICATION PRESCRIBED

<b>PLEASE UPDATE THIS LIST AFTER ANY PRESCRIPTION CHANGE</b>			
<b>NAME OF MEDICATION</b>	<b>STRENGTH</b>	<b>QUANTITY</b>	<b>TIMES A DAY</b>

### ALLERGIES AND OTHER RELEVANT OR USEFUL INFORMATION










# Notes

A series of horizontal dotted lines for taking notes.

