

Caring for People with Dementia



Information and Guidance Somerset

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Foreword

When working in the field of dementia one often meets dedicated carers who take on the role of looking after a loved one, tirelessly and without complaint, for many years.

One such carer is David Light, who cared for his wife Pam. David realised very early in his role as a carer that “useful and local” help and information, although available, was often difficult to find. He met Jim Delves, who is a former carer of his late wife, at a carer’s group meeting.

They discussed the possibility of working together to bring the information that had been gathered into the form of a guide, which would benefit carers of people who have dementia. From this collaboration came ‘Caring for People with Dementia’ which we hope will be of use to you as a carer.

The guide is designed to bring you the local information you will find useful in your role as a carer. 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 ‘Caring for People with Dementia’ when you have a specific problem or have a subject that you wish to know more about. The guide is designed to direct you to an organisation where you will be able to find the information you require.

It is our desire that we develop ‘Caring for People with Dementia’ as time progresses. Your opinions and comments would be welcome to help us in keeping this information up to date. Please contact: dlight36@gmail.com or jimdelves@yahoo.co.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.

The authors are grateful to the following organisations for their support of this guide:-

NHS Somerset
Somerset County Council
Somerset Partnership NHS Foundation Trust
REPoD (Rotarians Easing Problems of Dementia)

References:-

Age UK
Alzheimer’s Society
Somerset County Council

Further copies of the Somerset “Caring for People with Dementia” booklet can be purchased via Somerset Partnership NHS Foundation Trust. Enquires about cost can be made to the trust.

Telephone 01278 432000

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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. These 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 services. You will find extensive references to other services throughout this pathway.

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 a physical disease 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

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

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

Obtain information, factsheets and leaflets from:-

Alzheimer's Society

National Telephone 020 7423 3500

Regional Telephone 0117 967 2975

South and East Somerset 01935 473597

North and West Somerset 01934 514977

Younger Person with Dementia Worker 07525 404274

alzheimers.org.uk/factsheets

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- 403 What is dementia with Lewy bodies?
- 404 What is Fronto-temporal dementia (including Pick's disease)?
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- 444 Depression
- 518 What if I have dementia? (THIS FACTSHEET IS IMPORTANT TO READ)
- 524 Understanding and respecting the person with dementia
- 526 Coping with memory loss

Aged UK

Telephone 0800 00 99 66

www.ageuk.org.uk

Somerset County Council

County Hall Telephone 0845 345 9166

Somerset Direct Telephone 0845 345 9133

To access publications lists go to 1 www.somerset.gov.uk

2 Click on contact us

3 Click on services

4 In the search box type in carers

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

Section 2: General Information

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, organizations, 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 entries under this entry.

In case the cared for person wanders off or becomes lost, put emergency contact names, telephone numbers in their handbag, wallet or pocket. The Carers Emergency Card is available from your **Carers Assessment Worker or Carers Administrator 01373 455854**

Message in a bottle:

The system works by storing the cared for person's details in a clearly labelled plastic bottle, which is kept in their 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 the message bottle from your doctor's surgery, pharmacy, Age Concern, Neighbourhood Watch, Council Offices or telephone the **Lions Club 0845 833 2806**

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 metal, 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

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

- **Who Cares?**
Can be obtained free, as a download, from the Department of Health publication www.orderlinedh.gov.uk
- **Right Care Index**
Can be obtained free as a download or booklet from Right Care Index
- **Still Going Strong**
Can be obtained free from The Mental Health Foundation publication department **020 7803 1100, email mhf@mhf.org.uk**

As a carer you may find the following publications useful:-

- Caring for Maria; Bernard Heywood. (Heyward)
- Caring for Someone who has Dementia; Jane Brotchie – Age Concern England. Dementia, Alzheimers & Other Dementia; Harry Cayton, Nori Graham, James Warne
- Dementia; Cayton, Graham, Warner
- Have The Men Had Enough; Margaret Forster
- If Only I'd Known That, One Carer's Experiences; Susan Hartnell-Beavis
- Iris; John Bayley
- Is The Cooker Turned Off? Caring for an Older Person with Failing Memory; Josephine Woolf, Michael Woolf
- Keeping Busy, A Handbook of Activities; Nancy Mace (Foreword) James Dowlip
- Remind Me Who I Am Again; Linda Grant
- The Best Friend's Approach to Alzheimers Care; Virginia Bell, David Troyell
- The Selfish Pig's Guide to Caring; Hugh Marriott
- What to do when the doctor says it's early stage Alzheimers; Todd E Feinberg & Winnie Yu
- Your Guide to Alzheimers; Alistair Burns
- 36 Hour Day – Family Guide to Caring; The John Hopkins University Press, Paul R. McHugh (Foreword) et al

Information 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)**

Social care

Somerset County Council is responsible for many social care services in Somerset. The single point of contact for information and to access services is Somerset Direct, which can be contacted about health and social care for adults, help for older people, vulnerable adults, their carers and the registered disabled. For information contact **Somerset Direct, 0845 345 9133**

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 contact **Right Care Index**.

Registration of people with disabilities

Anyone who has a disability can apply to go on the register. Local concessions may be available. To find out more and to register, contact **Social Services, Adult Social Care County Hall, 0845 345 9166 or Somerset Direct, 0845 345 9133**

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. For information contact **HM Revenue and Customs 0845 010 9000**

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. To obtain details of the Blue Badge scheme contact **Somerset Direct, 0845 345 9133**

Discount parking

Residents of Somerset, who are Blue Badge holders, may be entitled to discount parking in Somerset car parks. For information contact your **District Council (Section 13 telephone numbers)**

National Radar key

The National Radar key system offers independent access to toilets for people with disabilities. A Radar key for use of the disabled toilets, a list of toilets for the disabled in your District Council area and where to obtain a key is available from your **District Council (Section 13 telephone numbers)**

Mobility and Disability Aids

Check your local taxi companies for purpose built wheelchair access taxis.

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

Bridgwater Office 01278 434254

Taunton Helpline 01278 445446

Taunton Office 01823 327900

Yeovil Office 01935 420889

Community Transport Services

Provides community transport services for disabled, older and socially isolated people

For information contact:-

Mendip 01749 330100

Sedgemoor 01278 434881

South Somerset 01935 411572

Taunton 01823 331266

West Somerset 01643 707848

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 0845 331 5000**

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 aids available include:-

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

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 or **Somerset District Council (Section 13 telephone numbers)**

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.

Obtain information, factsheets and leaflets from:-

Alzheimer's Society

National Telephone 020 7423 3500

Regional Telephone 0117 967 2975

South and East Somerset 01935 473597

North and West Somerset 01934 514977

Younger Person with Dementia Worker 07525 404274

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3 Click on services

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

Section 3: Carer Support

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 going through. 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 the Key Worker or Care Manager responsible for the cared for person. They will be able to help you get practical help in your caring role.

For information, support and confidential guidance, speak to trained advisers on the **Alzheimer's Society Dementia help line 0845 3000 336**

Carers' Assessment Workers (CAW)

Somerset Partnership NHS Foundation Trust employs Carers Assessment Workers, who are based in Community Mental Health Teams. Carers' Assessment Workers specialise in assessing the needs of Carers of someone with a mental health difficulty. They can provide advice on:-

- Carers' counselling
- Carers' education programmes
- Carers' help lines
- Getting a break or holiday either on your own or with the person you care for
- Help with day to day caring
- How to access benefits and information about financial and legal matters
- How to access help in a crisis
- Local carers' support groups

For information contact **Somerset Partnership NHS Foundation Trust 01278 432000**

Care First Counselling Service

This service is FREE and CONFIDENTIAL to all Carers in Somerset. The service also provides a 24 hour, 7 day a week counselling support line.

Carers can self-refer by phoning **Care First on 0800 197 4516**

Somerset Carers' Network

Somerset's newsletter for mental health carers is available from:-
01373 455854 or www.somersetcarers.org

Carers' Participation Group

This is an independent group promoting and supporting carer involvement in Somerset's mental health services which:-

- Actively seeks to include carers in the planning, provision and evaluation of services
- Helps to improve the quality of life for the carer
- Influences change in services
- Provides opportunities to share experiences with other people in a similar position
- Provides representatives to sit on planning groups in Somerset Partnership

To become involved or to find out more,

Contact the **Users' and Carers' Development Manager 01749 836606 / 07774 207458.**

Employment Support Service

The Employment Support Service supports carers to gain or retain paid employment on a full or part time basis. The Employment Support Service can help to:-

- By supporting you in your workplace
- Find out what type of job would suit you
- Find positive ways to tell employers about your carer responsibilities
- Link in with Jobcentre Plus and other support organisations
- Make paid work part of your plans for the future
- Prepare a C.V, complete job applications and prepare for job interviews
- Search for work in your local area
- With information and advice for your employer

For information contact the **Carers Employment Development Officer 01373 455819**

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 respite 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, including the Alzheimer's Society and Somerset Partnership NHS Foundation Trust. For information on **Carers Groups (Section 13 Telephone numbers)**

Carers' support groups for carers of older people with mental health problems

You may find it helpful to be able to talk to other family members / carers of people with a mental health condition. You will be made very welcome at your local meeting:-

- Alzheimer's Society and Somerset Partnership, Burnham-on-Sea.
The group is held in **Burnham-on-Sea 01278 786876 (Day Hospital)**
- Alzheimer's Society, Mid Somerset, Glastonbury, Street, Wells and Shepton Mallet.
The groups are held in **Street 01935 473597**
- Somerset Partnership, Bridgwater.
The group is held in **Bridgwater 01278 720250**

Memory Café

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 support for you and the cared for person.

They are run by the Alzheimer's Society, including partnerships between the voluntary sector, the NHS and local Authorities.

The idea of a memory café is to provide a social activity, along with the provision of information, to support people with dementia and their carers. If someone is worried about their memory they can come and gain information, support and talk to other people who are living with memory loss or dementia. The cafes are free to attend and complimentary refreshments are available.

For information on Memory cafes contact;

Alzheimer's Society 01935 473597 or 01934 514977

Singing for the Brain

Singing for the Brain is a group activity which has been carefully designed for all people with memory difficulties and their carers, to receive the many health benefits that are woven into the fun of singing. It is enjoyable, friendly and uplifting, giving many people a much needed boost in confidence, all led by a trained facilitator.

What can I expect?

We meet for tea, coffee, biscuits and a chat beforehand to help people to relax and get to know each other. Once the session starts, we sit in a circle and do some exercises to warm up the voice. Then the fun really begins by singing a range of songs, either unaccompanied or sometimes using musical instruments. Please note that no previous singing expertise is required.

To find out more information about Singing for the Brain

Contact the **Alzheimer's Society 01935 473597 or 01934 514977**

Talking Point – Online support for anyone affected by dementia

Talking point is a virtual support group for anyone who is affected by dementia. It is a place to ask for advice, share information, join in discussions and to feel supported. Anyone with access to the internet can browse the information on talking point, but if you want to communicate with others and ask your own questions, you will need to register. Signing up is easy:-

- 1. Visit alzheimers.org.uk/talkingpoint**
- 2. Click on the register link in the middle of the page.**
- 3. Follow the on screen instructions.**

Somerset Dementia Adviser Service

The Dementia Adviser Service is being hosted by the Alzheimer's Society in Somerset and will run in partnership with Somerset County Council and NHS Somerset. People with dementia can be referred through memory assessment services, Somerset Direct; GPs, Somerset Active Living Centres or be referred by yourself. When your loved one received a diagnosis of dementia it may have come as a shock or perhaps you were relieved that you can finally give the symptoms a name. The service is designed to ensure you get the most out of life, whilst living with dementia, by guiding you to all the information you need not only about the illness, but also where to find the most appropriate services in your local area. For further information regarding the Dementia Adviser service please contact the **Alzheimer's Society 01935 473597**

Dementia Support Worker for Younger People

The Dementia Support Worker for Younger People is an outreach worker and provides ongoing support and relevant information to younger people with dementia, their carers and families, either face to face at home, at one of the many events or via post, phone or email. Events for younger people and their carers include, musical memories, Singing for the Brain and health walks which will usually incorporate a visit to a national trust property or a local museum. For further information please contact

The Dementia Support Worker for Younger People 07525 404 274

Sitting Service

The sitting service enables carers to take a break, time off, with peace of mind. The sitting service provides fully trained staff to care for:-

- Older people
- People with learning difficulties
- People with physical disabilities or a mental health problem
- People with sensory loss

This service is available on a regular or on an occasional basis on any day of the week between 8.00am and 11.00pm. Sessions may last from two hours up to a maximum of eight hours each day. Information can be obtained from the person's care coordinator for whom you care for, or

Somerset Direct 0845 345 9133

Emergency Response Card

The Carers Emergency Card reads "I am a carer and look after..... In an emergency, please contact the number below to summon help for the person I care for". The card is carried in your hand bag or wallet. To obtain the Emergency Response card please contact your **Carers Assessment Worker or Carers Administrator 01373 455854**

Respite care (Short Break)

Respite care (also known as Short Break) 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. Information regarding this service can be obtained from your GP, **for specialist services Somerset Partnership NHS Foundation 01278 432000 or Somerset Direct 0845 345 9133**

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.

Obtain information, factsheets and leaflets from:-

Alzheimer's Society

National Telephone 020 7423 3500

Regional Telephone 0117 967 2975

South and East Somerset 01935 473597

North and West Somerset 01934 514977

Younger Person with Dementia Worker 07525 404274

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Aged UK

Telephone 0800 00 99 66

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4 In the search box type in carers

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

Section 4: Looking after Yourself

Part of doing your best is looking after yourself and 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 a break 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.

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.

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

To request a Home Safety contact

Devon and Somerset Fire and Rescue Service (Freephone) 0800 7311 822

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.

Emergency Telephone Electricity 0845 770 8090 Gas 0845 111 999 Water 0845 300600

Keep Warm Keep Well

The annual Keep Warm Keep Well campaign is aimed at financially disadvantaged older or disable people and their carers and families with young children on low incomes. It gives information on the health benefits of keeping warm in winter, providing advice on healthy eating and exercise, home heating and energy efficiency, and details of the grants and benefits available. For more information on how to keep warm and well in winter, Visit www.direct.gov.uk/keepwarmkeepwell

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 the 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;

Alzheimer's Society

National Telephone 020 7423 3500
Regional Telephone 0117 967 2975
South and East Somerset 01935 473597
North and West Somerset 01934 514977
Younger People with Dementia 07525 404274
alzheimers.org.uk/factsheets

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Age UK

Telephone 0800 00 99 66
www.ageuk.org.uk

Somerset County Council

County Hall Telephone 0845 345 9166
Somerset Direct Telephone 0845 345 9133

To access publication lists go to 1 www.somerset.gov.uk
2 Click on contact us
3 Click on services
4 In the search box type in carers

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

Section 5: Carers Rights and Assessments

Who is a carer?

A carer is someone of any age who provides, unpaid, a substantial amount of care on a regular basis for a parent, partner, relative or friend of any age who is ill, frail or disabled (mentally or physically).

Carers Assessment

The Carer's (Equal Opportunities) Act 2004

The Carer's (Equal Opportunities) Act 2004 places a legal duty on local authorities to inform carers of their right to an assessment of their needs in their caring role. When they carry out that assessment, they will also have a legal duty to consider any work, study and leisure interests that a carer may have.

You have a right to a Carer's Assessment if you are over 16 and provide, or intend to provide, regular and substantial care to someone over 18. The Carer's Assessment should look at whether you wish to continue caring and your needs. This is not an assessment of how good you are at caring, but is about the support that may be available to help you in your role as a carer. You can ask for an assessment from your Care Trust regardless of whether the person you care for receives services from that Care Trust. Under the Act, carers are entitled to services in their own right. These services are defined as anything that promotes the health and wellbeing of the carers. The help can range from driving lessons, counselling and information and advice. The Care Trust is able to charge carers for some of the services they receive.

If an assessment concludes that services are required, these must be provided. Such services may include aids and adaptations to the home, meals on wheels, home care, respite schemes, care, residential and nursing care.

To request a carers assessment call **Somerset Direct 0845 345 9133**

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.

Obtain information, factsheets and leaflets from:-

Alzheimer's Society

National Telephone 020 7423 3500

Regional Telephone 0117 967 2975

South and East Somerset 01935 473597

North and West Somerset 01934 514977

Younger Person with Dementia Worker 07525 404274

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Age UK

Telephone 0800 00 99 66

www.ageuk.org.uk

Somerset County Council

County Hall Telephone 0845 345 9166

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For further details see Section 13(Telephone numbers etc) and 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

For training courses contact your local Carers Support Worker on **Somerset Direct 0845 345 9133** or **www.somersetcarers.org**

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

BOOK IT NOW

For further details see Section 13(Telephone numbers etc) and 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 parents 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 in your best interests. You can also in a similar way appoint someone to make decisions about health and personal welfare.

Parents 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 1st 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, when 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 sweeping 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 giving a court the power to appoint a deputy to act on the cared for persons financial behalf. It can freeze 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 to have all the 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:-

Alzheimer's Society

National Telephone 020 7423 3500

Regional Telephone 0117 967 2975

South and East Somerset 01935 473597

North and West Somerset 01934 514977

Younger Person with Dementia Worker 07525 404274

alzheimers.org.uk/factsheets

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Age UK

Telephone 0800 00 99 66

www.ageuk.org.uk

Somerset County Council

County Hall Telephone 0845 345 9166

Somerset Direct Telephone 0845 345 9133

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Department of Health

www.dh.gov.uk/en/socialCare/Deliveringadultsocialcare/MentalCapacityAct

Mental Capacity Act and Deprivation of Liberty Information/Leaflets

For further details see Section 13(Telephone numbers etc) and 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.

For information contact

Somerset Direct 0845 345 9133, your local Citizens Advice Bureau 020 7833 2181 or the Disability Benefits Helpline 0800 882200.

Possible benefits to claim are:-

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

Direct payments

These are payments made to individuals by the Social Service Department 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. You can also receive direct payments if you are a carer who has been assessed as needing support in your own right.

For details contact **Somerset Direct 0845 345 9133**

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.

For details contact

Somerset Direct 0845 3459133 or your local Citizens Advice Bureau 020 7833 2181

Appointee

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:-

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

Obtain information, factsheets and leaflets from:-

Alzheimer's Society

National Telephone 020 7423 3500

Regional Telephone 0117 967 2975

South and East Somerset 01935 473597

North and West Somerset 01934 514977

Younger Person with Dementia Worker 07525 404274

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Age UK

Telephone 0800 00 99 66

www.ageuk.org.uk

Somerset County Council

County Hall Telephone 0845 345 9166

Somerset Direct Telephone 0845 345 9133

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2 Click on contact us

3 Click on services

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For further details see Section 13(Telephone numbers etc) and 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 do just that.

The Social 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 putting to bed in the evenings, supervising the administration of medication and preparation of meals. They will be financially assessed to see if they will need to make a financial contribution towards the cost of any services.

For information contact **Somerset Direct 0845 345 9133**

This service is provided by a private company and funded by social services within certain financial guide lines.

To access domiciliary care call **Somerset Direct 0845 345 9133**

Domiciliary care can also be arranged by contacting your doctor, hospital, social worker or Key Worker / Care Manager.

Shopping and housework are also undertaken, but must be paid for separately.

Obtain information, factsheets and leaflets from:-

Age UK

Telephone 0800 00 99 66
www.ageuk.org.uk

Somerset County Council

County Hall Telephone 0845 345 9166
Somerset Direct Telephone 0845 345 9133

To access publications lists go to 1 www.somerset.gov.uk

2 Click on contact us

3 Click on services

4 In the search box type in carers

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.

There are four main types of care homes:-

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.

Specialised Residential Care Home (SRC)

Specialised Residential Care provides high quality residential care, specially designed for older people with dementia. The emphasis within the home is on person centred care and on providing an environment that promotes well being and independence. The staff have specific training in supporting people with dementia and they receive advice and guidance from a Specialist Care Development Nurse who visits the home twice a week.

The homes have been developed in a range of different settings, including larger and smaller homes and in units attached to a larger home. They will all conform to the detailed Accreditation Specification.

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.

Specialist 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 have been inspected by the Care Quality Commission (CQC) and will assist you in this step. Do not be bullied into moving the cared for person, 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.

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 service you well.

For information contact **Somerset Direct 0845 345 9133**

Choose your 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 specialize in dementia care. Many of the featured homes also accommodate day and short term respite care.

Obtain information, factsheets and leaflets from:-

Alzheimer's Society

National Telephone 020 7423 3500

Regional Telephone 0117 967 2975

South and East Somerset 01935 473597

North and West Somerset 01934 514977

Younger Person with Dementia Worker 07525 404274

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Age UK

Telephone 0800 00 99 66

www.ageuk.org.uk

Somerset County Council

County Hall Telephone 0845 345 9166

Somerset Direct Telephone 0845 345 9133

To access publications lists go to 1 www.somerset.gov.uk

2 Click on contact us

3 Click on services

4 In the search box type in carers

For further details see Section 13(Telephone numbers etc) and 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.

Palliative care

Palliative care services are intended to keep the person as comfortable as possible and to insure 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.

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

Age UK can supply factsheets, offer free advice and support

For information contact **Age UK 0800 00 99 66**

Alzheimer's Society supply factsheets, books, information and support through local branches of the society.

For information contact **Alzheimer's Society 0207 423 3500**

Care First – Carers Counselling Service (provided by Somerset County Council)

Is a free and confidential service to all carers in Somerset to which they can self refer. This service also provides a 24 hour, 7 day a week

For counselling support line **Care First 0800 197 4516**

Citizens Advice Bureau (CAB) helps 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 (CAB) 0207 833 2181**

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

For information contact **Cruse Bereavement Care 0844 477 9400**

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 contact **Samaritans 0845 790 9090**

Obtain information, factsheets and leaflets from:-

Alzheimer's Society

National Telephone 020 7423 3500
Regional Telephone 0117 967 2975
South and East Somerset 01935 473597
North and West Somerset 01934 514977
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Age UK

Telephone 0800 00 99 66
www.ageuk.org.uk

Somerset County Council

County Hall Telephone 0845 345 9166
Somerset Direct Telephone 0845 345 9133

To access publications lists go to

- 1 www.somerset.gov.uk
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- 4 In the search box type in carers

For further details see Section 13(Telephone numbers etc) and 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 Professional
CAMCOG	Cambridge Cognitive Assessment
CAW	Carers 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
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
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
MIND	National mental health charity
MMSE	Mini Mental State Examination
MND	Motor Neurone Disease
MRI SCAN	Magnetic Resonance Imaging
MS	Multiple Sclerosis
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
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
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
TYM TEST	Test your memory test
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
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
Age UK (Formerly Age Concern and Help the Aged)	National	0800 00 99 66 www.ageuk.org.uk
Alzheimer's Society	National	020 7423 3500 www.alzheimers.org.uk
Dementia Adviser Service		01935 410547
Dementia Helpline		0845 3000 336
Regional		0117 967 2975
North and West Somerset		01934 514977
South and East Somerset		01935 473597
Younger People with Dementia Worker		07525 404274
Benefits		
Pensions Office (Benefits Agency)	National	0800 882 200
	National	0845 606 0265
Benefits Check		
Somerset Direct		0845 345 9133
Citizens Advice Bureaux (CAB)	National	020 78332181
Taunton		01823 282235
Mid Somerset – Shepton Mallet		01749 343010
South Somerset - Yeovil		01935 410561
West Somerset Advice Bureau		01643 704624
Citizens Advice Bureau		01278 455236 / 01278 446884
Disability Benefits Helpline		0800 882 200
Blue Badge Parking Scheme		
Somerset Direct		0845 345 9133
		01749 648999
British Red Cross	National Delivery Service	0845 331 3331 0845 331 3331 www.redcross.org.uk
Care First Carers Counselling Service		0800 174 319
Care Quality Commission (CQC)		03000 616 161 www.cqc.org.uk
Carer Support		
Carers Assessment Workers (Older Persons) Taunton and Somerset Coast Mendip and South Somerset		01278 720220 / 0773 8898747 01373 455814 / 0790 9877657
Carers Support Workers Somerset Direct		0845 345 9133
Carer Support Groups for all Carers in Somerset		
Bridgwater Carers Group Meets on the 3 rd Friday of each month from 10.30am - 12.30pm		01278 426408

Bruton Carers Group Meets on the 2 nd Wednesday of each month from 10.30am - 12.00pm	01963 31720
Burnham on Sea Carers Group Meets on the 2 nd Monday of each month from 11.00am - 12.30pm	01278 793729
Crewkerne Carers Support Group Meets on the 1 st Tuesday of each month from 10.30am - 12.30pm	01458 252617
Dulverton Carers Support Group Meets at various locations on the last Tuesday of each month at 10.30am onwards	01643 707997
Frome Carers Group Meets on the 1 st Thursday of each month from 10.30am - 12.00pm	07917 837480
Highbridge Carers Group Meets on the 4 th Tuesday of each month from 10.30am - 12.00pm	01278 793729
Langport Carers Support Group Meets on the 4 th Wednesday of each month From 11.00am – 12.30pm	01458 252617
North Sedgemoor Carers Group Meets on the 2 nd Monday of each month from 11.00am - 12.30pm	01278 793729
Street & Glastonbury Carers Group (in partnership with Active Living) Meets on the 2 nd Monday of each month from 10.00am - 12.00pm	07917 837482
Taunton and South Somerset District Carers Support Group Meets on the 3 rd Friday of each month from 1.30pm - 4.30pm	07737 432153
Wellington Carers Support Group Meets on the 1 st Thursday of each month from 2.00pm - 3.30pm	01935 431725
Wells Carers Group Meets on the 1 st Tuesday of each month from 10.30am - 12.00pm	07917 837480
West Somerset Carers Group Meets on the 1 st Thursday of each month from 2.00pm – 3.30pm	01643 707997
Williton Carers Group Meets on the last Thursday of each month from 7.00pm - 8.30pm	01643 707997
Wincanton Carers Support Group Meets on the 2 nd Monday of each month from 10.30am - 12.00pm	01963 31730
Yeovil Carers Group Meets on the 2 nd Thursday of each month from 10.30am - 12.00pm	01935 433013

Carers Groups for carers of people with dementia

Somerset Partnership NHS Foundation Trust, Burnham on Sea Meets alternate Wednesdays from 2.30pm – 2.30pm	01278 786876
Somerset Partnership NHS Foundation Trust, Bridgwater Meets on the 2 nd Wednesday of each month from 2.00pm – 3.30pm	01278 720220

Carers Training Courses

St John Ambulance (Carer Training)	01823 345922 www.sja.org.uk
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Carers U K National helpline (free phone)	0808 808 7777
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Citizens Advice Bureaux (CAB) National	020 7833 2181 www.citizensadvice.org.uk
North Somerset Weston-Super-Mare	0844 826969
North East Somerset Midsummer Norton	01761 418599
Sedgemoor Bridgewater	01278 455236
South East Somerset Yeovil	01935 421167
South Somerset Yeovil	01935 421167
Taunton	01823 282235

Community Transport Somerset

Mendip Community Transport Mendip Dial-a-Ride Service Dial-a-Ride cars	01749 344141 01749 330100
Sedgemoor Community Transport Isle of Wedmore community bus	01278 434881 01934 712160
South Somerset Mini Bus Links Community Cars Cary and Ansford Community Bus Crewkerne Voluntary Transport Ilminster Community Transport Wincanton Community Transport	01935 411572 01935 475914 01935 477399 01935 411572 01963 350895 01460 75759 01460 55540 01963 33605
Taunton Red Cross Transport The Wivey Link	01823 331266 01326 370924 01984 624666
West Somerset Exmoor Community Bus	01643 707484 01398 323665

Cruse	0844 477 9400 www.crusebreavimentcare.co.uk
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D.H.S. Health Care Ltd Free phone	0800 783 76 54
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Disability Information Service	0845 1551 005
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H.M. Revenue and Customs (VAT)	0845 010 9000 www.hmrc.gov.uk
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Key Care Solutions Free search facility for finding the right care home or day centre	0844 414 5827 www.keycaresolutions.co.uk info@keycaresolutions.co.uk
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Memory Cafés

Bridgwater	01934 514977
Chard	01935 473597
Frome	01935 473597
Minehead	01934 514977
Sherborne	01935 473597
Street	01935 473597
Taunton	01934 514977
Yeovil	01935 473597

Mencap	0808 808 1111
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Message in a bottle

Lions Club	0845 833 2806 miab@lions105sw.org.uk
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NHS Direct	0845 46 47
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NHS Somerset (Formally Somerset Primary Care Trust)	01935 384000 www.somerset-health.org.uk
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Office of the Public Guardian	0845 330 2900 www.publicguardian.gov.uk
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Patient Advice and Liaison Service (PALS)	0800 0851 067
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Pensions Office Benefits Agency	0800 882 200 0845 60 60 265 www.thepensionsservice.gov.uk
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Personal Alarm System

Age Concern	0800 772 2661
Call 24 Hour	0800 085 0407 www.call24hour.com

Police Avon and Somerset (non-emergency)	0845 456 7000
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Princess Royal Trust For Carers	0207 480 7788
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Publications

Who Cares? Department of Health publication department	0300 1231 002 www.orderlinedh.gov.uk
Right Care Index A comprehensive health and social care directory for Devon	01872 321327 www.rightcareindex.com mail@rightcareindex.com
Still Going Strong. The Mental Health Foundation publication department	0207 8031 100 / 08457 909 090 Email mhf@mhf.org.uk

Radar key

Royal Association for Disability and Rehabilitation (RADAR)	020 7250 3222 www.radar.org.uk or the information point at your local library
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Registration Office (Birth, Marriage, Death)

Bridgwater (Sedgemoor)	01278 422527
Shepton Mallet (Mendip)	01749 343928
Taunton	01823 282251
Williton (West Somerset)	01984 633116
Yeovil (South Somerset)	01935 411230

Rotarians Easing Problems of Dementia (REPoD)	01822 852102 www.repod.org.uk
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Royal National Institute for the Blind	0845 766 9999
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Royal National Institute for the Deaf	0808 808 0123
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Samaritans	0845 790 9090 www.samaritans.org.uk
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Saneline	0845 767 8000
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Shopmobility

Bridgwater Office	01278 434254
Taunton Office	01823 327900
Taunton Helpline	01278 445446
Yeovil Office	01935 420889

Singing for the brain

Castle Cary	01935 473597
Ilminster	01935 473597
Minehead	01934 514977
Sherborne	01935 473597
Taunton	01934 514977
Wells	01935 473597

Social Services

Somerset Social Services	0845 345 9133
SHIP – New name, Somerset West Care 7 Repair Limited	01278 442400
Signposts	0800 317 220

Somerset Care and Repair

The Taunton Deane and South Somerset Community Handyman Service	01935 462462
Mendip Care and Repair Ltd	01749 345379
Magna Gardener & Handyperson Service Magna Housing Association, West Somerset	0800 138 6107

Somerset Counselling Service for Carers	0800 174 319
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Somerset County Council	0845 345 9166 www.somerset.gov.uk
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Somerset Direct	0845 345 9133
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Somerset District Councils

Mendip District Council	01749 648999
Sedgemoor District Council	0845 408 2540
South Somerset District Council	01935 642642
Taunton Dean Borough Council	01823 356356
West Somerset District Council	01643 703704

Somerset Doctors NHS OUT OF HOUR'S URGENT GP SERVICE	0845 408 800
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Somerset Partnership NHS Foundation Trust

Somerset Partnership NHS Foundation Trust Headquarters. Provides specialist health and social care services for people in Somerset with severe and enduring mental health problems.	01278 432000 www.sompar.nhs.uk
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Somerset Primary Care Trust (Now NHS Somerset)	01935 384000 www.somerset-health.org.uk
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St John Ambulance (Carer training for Somerset)	01823 345922 www.sja.org.uk
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Stroke Association National Help line	0845 3033 100
Somerset	01823 276798
East Somerset	01278 789365
West Somerset	01984 634276
	www.stroke.org.uk
	Email Info@stroke.org.uk

Utility companies (Emergency Telephone Numbers)

Electricity	0845 770 8090
Gas	0845 111 999
Water	0845 300 600

Section 14: Factsheets and Leaflets

Age UK factsheets

Have a wide range of factsheets which can be obtained from:-
www.age.org.uk or telephone 020 876 57200

Alzheimer's factsheets

Have a wide range of factsheets which can be obtained from:-
www.alzheimers.org.uk/factsheets or telephone 020 7423 3500

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
406	Aluminium and Alzheimer's disease
407	Drug treatments for Alzheimer's disease
408	Dementia: drugs to relieve depression and behavioural symptoms
417	The later stages of dementia
427	What is Creutzfeldt-Jakob disease (CJD)?
430	Learning disabilities and dementia
434	Complementary and alternative medicine and dementia
438	What is Korsakoff's syndrome?
440	Younger people with dementia
442	Rarer causes of dementia
444	Depression
446	What is HIV-related cognitive impairment?
450	Am I at risk of developing dementia?
456	The brain and behaviour
458	The progression of dementia
470	Mild cognitive impairment
479	What is posterior cortical atrophy (PCA)?
520	Hallucinations and delusions
527	Visuoperceptual difficulties in dementia

Emotional and practical support

409	Volunteering for research into dementia
410	Brain tissue donations
412	Voluntary organisations
428	Adaptations, improvements and repairs to the home
429	Equipment to help with disability
436	Mini mental state examination (MMSE)
437	Assistive technology
439	Driving and dementia
445	Counselling: how can it help?
448	Dental care and dementia
455	Festivals, holidays and celebrations
462	Respite care
471	After a diagnosis
474	Travelling and going on holiday
475	Frequently asked legal questions
476	Selecting a care home
480	Understanding and respecting lesbian and gay people

482	Choosing residential accommodation for lesbian and gay people
500	Communicating
501	Moving and walking about
502	Coping with incontinence
503	Safety in the home
504	Washing and bathing
505	Keeping active and staying involved
507	Grief and bereavement
509	Dealing with aggressive behaviour
510	Dressing
511	Eating
512	Pressure sores
514	Sex and dementia
515	Dementia and children or young people
516	Dealing with guilt
517	Living alone
518	What if I have dementia?
521	Maintaining every day skills
522	Staying healthy
523	Carers: looking after yourself
524	Understanding and respecting the person with dementia
525	Unusual behaviour
526	Coping with memory loss

Healthcare

418	Community care assessment
425	How the GP can help
426	Diagnosis and assessment
451	What standards of care can people expect from a care home?
452	Assessments for NHS-funded nursing care
453	Hospital discharge
454	How health and social care professionals can help
465	Choices in care
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 2007 and Guardianship
460	Mental Capacity Act 2005
463	Advance decision
467	Financial and legal affairs
469	When does the local authority pay for care?
472	Enduring power of attorney and lasting powers of attorney
473	Direct payments
481	Legal issues for lesbian and gay people
483	Deprivation of liberty Safeguards

Somerset County Council Leaflets

To access publications lists go to:-

1. www.somerset.gov.uk
2. Click on contact us
3. Click on services
4. In the search box type in Carers



First published in July 2010. Revised September 2011
This publication is supported by Somerset Partnership NHS Foundation Trust,
Somerset County Council, NHS Somerset and
REPoD (Rotarians Easing Problems of Dementia).