

# Caring for someone with dementia



# **Caring for someone with Dementia Handbook**

## **An introduction**

This information has been designed to help you as a carer of someone with dementia. It has information about dementia, your caring role and gives you useful details about the local and national support and services that are there to support you and the person you care for.

It has been organised into different sections based upon a range of subjects. It does not contain everything there is to know, but does contain the details of organisations that you can contact for more advice and support.

The handbook does contain a lot of information which may appear to be overwhelming but you do not need to remember all of this information – you can simply refer to this handbook as and when you need it.

## **Disclaimer**

The content of this guide has been checked for accuracy at the time of publication, but beyond this date we cannot accept responsibility if information is out of date. It is designed to provide helpful information and signpost you to 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 and the care of a loved one or a friend.

## **Acknowledgements**

This handbook has been based on the document "Caring for Dementia: Dementia Carers' Pathways Devon", which was produced by David Light and Jim Delves. Wiltshire would like to thank both David and Jim for sharing their work and ensuring that carers have access to good quality information.

Wiltshire Council would also like to thank the carers and organisations in Wiltshire who have contributed to the production of this document.

## What is in this handbook?

Section 1 - What is dementia? .....	Page 4
Section 2 - Getting a diagnosis .....	Page 5
Section 3 - Becoming a carer .....	Page 6
Section 4 - Assessment of carers' needs .....	Page 7
Section 5 - Support for carers .....	Page 8
Section 6 - Staying healthy .....	Page 12
Section 7 - Staying safe .....	Page 14
Section 8 – Relationships .....	Page 16
Section 9 - Carer training .....	Page 17
Section 10 - Financial and legal implications .....	Page 18
Section 11 – Benefits .....	Page 22
Section 12 - Working and caring .....	Page 24
Section 13 - Hospitals and discharge .....	Page 26
Section 14 - Working with professionals .....	Page 28
Section 15 – Telecare .....	Page 29
Section 16 - Sheltered housing .....	Page 29
Section 17 - Extra care housing .....	Page 30
Section 18 - Domiciliary care .....	Page 30
Section 19 - Residential care .....	Page 31
Section 20 – Counselling .....	Page 33
Section 21 - Wiltshire Council factsheets .....	Page 34
Section 22 - Alzheimer's Society factsheets .....	Page 35
Section 23 - Age UK factsheets .....	Page 37
Section 24 - Useful contact details .....	Page 39
Section 25 - Your notes .....	Page 42
Section 26 - Your useful contacts .....	Page 46
Section 27 - Your record of telephone conversations .....	Page 48
Section 28 – Emergencies .....	Page 50
Section 29 - How to make a complaint, comment or compliment .....	Page 51

## **Section 1 - What is dementia?**

If you, or a friend or relative, have been diagnosed with dementia, you may be feeling anxious or confused. You may not know what dementia is.

The term 'dementia' is used to describe the symptoms that might be brought about by one or more illnesses which may affect the brain. These include Alzheimer's disease, vascular dementia and dementia with Lewy bodies.

Dementia is progressive, which means the symptoms will gradually get worse. How fast dementia progresses will depend on the individual. Each person is different and will experience dementia in their own way.

Symptoms of dementia include:

- Loss of memory – for example, forgetting the way home from the shops, or being unable to remember names and places, or what happened earlier the same day.
- Mood changes – particularly as parts of the brain that control emotion are affected by disease. People with dementia may also feel sad, frightened or angry about what is happening to them.
- Communication problems – a decline in the ability to talk, read and write.
- Difficulty with every day tasks.
- Loss of logic and ability to reason or use initiative.
- Disorientation in time and place.

In the later stages of dementia, the person affected will have problems carrying out everyday tasks, and may become increasingly dependent on other people.

There are many different illnesses which may lead to dementia, and to give detailed information on all of these would be beyond the scope of this handbook. If you would like further information on a particular type of dementia please contact your local Alzheimer's organisations. (Details can be found in section 24).

The national Alzheimer's Society has a range of useful factsheets which provide more information on dementia and the different stages of dementia. More details can be found in section 22.

A Mental Health Directory for Wiltshire is also available from Wiltshire Mind. This Directory provides information on the range of mental health support services available to people in Wiltshire. (Contact details can be found in section 24).

## **Section 2 - Getting a diagnosis**

It is very important to get a proper diagnosis from a specialist. If you or the person you are looking after has concerns about their memory, the first person to speak to is your GP. A diagnosis will help the doctor rule out any physical illnesses that might have similar symptoms to dementia, including depression, urinary tract infections and substance misuse (drugs or alcohol). Once the doctor has checked for any easily treatable causes, they can then request a specialist assessment from the memory service if necessary.

The memory service is for people who are concerned about their memory and think it is affecting their day to day life. If the person you look after is referred to the service, an assessor will talk with them about their memory difficulties, complete some checks and discuss the impact of any problems or issues. This may be followed by some further checks so that a diagnosis can be made. The memory service encourages the person with memory problems to take someone, such as a family member, with them so that everyone can be involved where appropriate. The implications of a diagnosis will be discussed, with information and advice being given and there will be the opportunity to discuss any possible medication and support that may help the person to manage the situation.

Whether you are someone with dementia or a carer, a diagnosis can help you prepare and plan for the future. However, having a diagnosis made may not automatically solve all of your problems. It may be reassuring to have it confirmed that the person really is ill – and you can begin to prepare for the changes that will have to take place in your lives. However, it will take a while for the implications of the disease to sink in. It is important to remember that many people in the early stages of dementia, even after having a diagnosis, can live a fairly independent life with support.

### **Section 3 - Becoming a carer**

A carer is:

“someone who provides unpaid support to a family member, partner, friend or neighbour. This could be because the person is ill, frail, disabled or has mental health or substance misuse problems.”

Therefore, if you are looking after someone with dementia then you are a carer. However, many carers do not recognise themselves as carers, because they see the support and help that they give as part of their normal relationship with the person they care for.

Anybody can become a carer. Becoming a carer can happen suddenly or it might be a gradual process which grows over time. The latter is often the case if you are looking after someone with dementia.

You might also find as a carer, that your caring responsibilities may vary over time and may be difficult to predict day to day.

Your caring role may also continue whilst the person being cared for is in hospital or another setting, such as a nursing home.

Everybody is different and so everybody who becomes a carer will find the experience to be different. However, many carers find that becoming a carer is an emotional process, which can often happen without preparation. You may feel that you have a lot to learn all of a sudden and that you are not as prepared as you would like to be. Many carers also have times when they may feel resentful about having to care for someone and then feel guilty about these types of feelings.

It is important to remember that you are not the only person feeling like this. Peer support is important and talking to other carers who are going through the same feelings and changes in their lives can be useful. For more information on Carer Support Wiltshire which runs support groups, see section 5.

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 or Adult Care Teams are 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 their carers. Their role is to provide community interventions where possible, to help people stay in their own homes. Through an assessment process, they will look at what help you and the person that you care for need and will be able to advise and support you appropriately, depending on your circumstances. For more information call the customer advisors at Wiltshire Council – contact details in section 24.

## **Section 4 - Assessment of a carers' needs**

If you are providing, or intend to provide, a substantial amount of care on a regular basis to the person you look after, then you are entitled to an assessment of your needs as a carer under the Carers (Recognition and Services) Act 1995. You can ask for your own assessment at any time, even if the person you care for does not want an assessment or services.

Your assessment will be completed by someone from the Department of Community Services or from the local Community Mental Health Team.

An assessment of carers' needs is an opportunity to:

- Talk and think about your own needs as a carer.
- Share your experience of caring and have your role as a carer recognised.
- Be given information and advice.
- Identify and discuss any difficulties that you may have.
- Make emergency plans if you are ill or cannot continue in your caring role.

An assessment is not about your capability to care but it will look at ways in which to help you in your caring role. This may include arranging services to help you in your caring role or giving you a Carers Direct Payment, which is a sum of money so that you can buy your own support.

This support can help you to continue with your caring responsibilities if you wish to, to maintain your own health and well-being or to help you when you can no longer care.

It is your choice whether you have a separate assessment of your needs or a joint assessment with the person you care for. A joint assessment is when your views and needs are taken into account when the person you care for is being assessed.

If you choose not to have an assessment, it does not stop the person you care for from receiving services.

The assessment of your needs as a carer does NOT include a financial assessment.

For more information contact the customer advisors at Wiltshire Council or your local Community Mental Health Team. Contact details can be found in section 24.

## **Section 5 - Support for carers**

### **Carer support**

Carer Support Wiltshire works to help carers in their caring role and they provide a range of information and support.

You can ask them all types of questions and if they do not know the answer then they will find out for you and point you in the right direction. They have workers who will come and visit you in your home if that is easiest for you. They also organise a number of events, activities and groups where you can relax, find out more about being a carer and talk to other carers who are in similar situations to you.

Contact details can be found in section 24.

### **Carers direct payments**

These are sums of money that are given to a carer to support them in their caring role, so that they can buy their own services. Direct payments are part of what is called the personalisation agenda. This is a way of delivering services that is designed to give you more choice and control over the services you receive. To access carers direct payments you need to have an assessment of your caring needs (see section 4), which will decide if you are eligible. If you are eligible, then you will agree with your care manager how you can use this payment. Examples of how carers direct payments can be used include a break or holiday, help around the home with domestic tasks or equipment that will help you in your caring role.

If the person you care for is entitled to a direct payment following their own assessment then you may be able to become a 'suitable person' to receive their direct payment if they lack the capacity to consent to receive it themselves.

### **Timeout**

Timeout activities are run by Carer Support Wiltshire and are free. They include lots of different social, leisure and relaxation activities for carers who cannot take breaks elsewhere. This can be a great opportunity to have a break from caring, have some time to yourself and meet and socialise with other carers.

Call Carer Support Wiltshire for more information – contact details can be found in section 24.

### **Alzheimer's organisations**

There are Alzheimer's organisations in Wiltshire and they provide specialist support and information to people with dementia and their carers. These are:

- Alzheimer's Support West Wiltshire and Kennet (East Wilts)
- Alzheimer's Society North Wiltshire
- Alzheimer's Society Salisbury

They offer a number of activities, services and groups for both yourself as a carer and also for the person you care for.

Contact details can be found in section 24.

### **Memory cafés**

Memory cafés offer a friendly, relaxed and welcoming setting where people with dementia and their families and carers can meet others in a similar situation, find out how and where to get help and to share stories with others. The memory cafés are run by Alzheimer's organisations, and are held on a regular basis across Wiltshire

Contact details for the Alzheimer's organisations can be found in section 24.

### **Carers' emergency card**

The carers' emergency card will identify you as a carer in the event of an accident or an emergency. It is the size of a credit card so it will fit in a wallet or purse. It is designed to give you peace of mind. You can be less anxious about going out and leaving the person you care for alone at home. If you have an accident or suddenly fall ill, the emergency services finding the card will know you are a carer and be able to contact the 24 hour emergency response service. The card is free and available to all carers in Wiltshire.

Contact details can be found in section 24.

### **Carers' breaks and other support in your caring role**

You may be eligible for additional support to help you in your caring role. There are lots of different types of support available – it could be through regular short breaks from caring, help around the home or a piece of equipment that would help you. This support can be accessed through an Assessment of your Carer's Needs (more information in section 4). If you are eligible then you could receive either money to buy your own support or your support will be organised for you.

### **Advocacy**

Sometimes it can be difficult to ask for information and services. SWAN Advocacy Network is an independent advocacy charity, which supports and empowers individuals across Wiltshire to ask for the information and services they need in order to improve their own health and well being. The service is free and confidential.

Contact details for SWAN Advocacy can be found in section 24.

### **Blue Badge Scheme**

The Blue Badge Scheme (formerly the Orange Badge Scheme) provides considerable parking concessions for people with severe walking difficulties who travel as either drivers or passengers.

The badge is issued solely for the use of the disabled person, however applications from the public will also be considered when there is difficulty in walking from time to time.

Contact details can be found in section 24.

### **Carers GP Registers**

Your GP surgery will hold a Carers Register. If you are not already on it, ask the receptionist or your GP to add you to it. The registers work differently in all surgeries, but as a result of being on it you may be able to access more flexible appointments, flu vaccines and annual health checks. Contact your GP surgery for more information.

### **Singing for the Brain**

Singing for the Brain is a service for people with dementia and their carers and is developed and led by the Alzheimer's organisations around the principles of music therapy and singing. The groups are run in Wiltshire to allow people with dementia and their carers to enjoy time together and meet others in a stimulating and supportive social environment.

Contact details for the Alzheimer's organisations can be found in section 24.

### **Libraries**

Libraries offer carers additional support. You are entitled to a carers' category library card. This means you can have books for six weeks instead of the usual three week loan and request Wiltshire Library stock free of charge. Carers and those people they care for are also able to have the Home Library Service. This service is provided by volunteers who will work with library staff to deliver particular books, talking books and DVDs of interest either fortnightly or monthly at a convenient time to the carer's home. For more information, contact your local library.

### **Memory Support Group in Salisbury**

Elizabeth Bartlett who is an approved Wiltshire dementia trainer and a counsellor runs a memory support group with Dr Marie Mills, a psychologist. This group offers emotional support and takes place in an informal setting in Salisbury for the person that you look after. You will also be able meet other carers of people with dementia as there is a carers' conversation group which meets at the same time in another room, whilst the person you are caring for is in the memory support group. For more information please contact Elizabeth on 07812 381463 or [elizabethbartlett@ntlworld.com](mailto:elizabethbartlett@ntlworld.com)

### **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. You can add items to the box as time progresses.

### **My Life Book**

Make a 'My Life Book' 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 past and present is another idea. The list is endless, so you can use your own ideas too.

### **This is me**

'This is me' is a simple and practical tool that someone going into hospital can give to staff to help them understand the condition. It provides a 'snapshot' of the person with dementia, giving information about them as an individual, such as needs, preferences, likes, dislikes and interests.

This should enable staff to treat each person as an individual, thereby reducing distress for them and their carers and helping to prevent issues such as malnutrition and dehydration.

For more information contact your local Alzheimer's organisation – see in section 24.

## Section 6 - Staying healthy

It is important for you as a carer to take care of yourself, as well as the person you care for. Caring can be hard work, both physically and emotionally and without a break from caring and a little time spent on yourself you may find that your own health gets worse. Even a short break away from your caring role can give you the boost you need.

Looking after yourself can be done in many different ways:

- Taking a break from caring
  - A short break can give you the chance to relax. You might want to do something you enjoy such as seeing friends, taking a walk or even having a long bath in peace. You may be able to do this by having someone to come and stay with the person you care for or by using a day centre.
  - A longer break can help you get things sorted and recharge your batteries. You can speak to your GP or social worker about this. Make sure that you tell them that you need a break so that they can help you.
- Talking
  - Sharing how you are feeling with other carers or a professional can help. It is very likely that there are a lot of other carers who feel the same way as you.
  - Support groups are held across Wiltshire where carers can meet other carers in similar circumstances. They may be able to show you techniques to deal with certain situations or simply be a good listener.
  - NHS Counselling services and other psychological support tools can be found at GP surgeries.
- Eating healthy
  - Caring can often take up a lot of your time and cooking may be the last thing you feel like doing, but it is important that both you and the person you care for eat healthily.
  - As a carer a healthy diet will help you stay well and will make sure that you have the energy that you need.
  - You may find that the appetite of the person you care for changes. This is because dementia can affect a person's relationship with food. For some people with dementia, eating can become difficult or they may want to eat more food than they need.
  - Making some small changes can help to make eating easier and less stressful.
  - You can talk to your doctor about how you and the person you care for can eat healthily. They may then be able to refer you to a specialist, such as a dietician, occupational therapist or speech and language therapist.

- Moving and handling
  - As a carer you may need to lift and move the person you care for. Doing this incorrectly can be dangerous and can you cause you problems such as developing a problem with your back.
  - There is advice and equipment available to help you to carry and lift correctly. You can talk to your social worker or contact the customer advisors at Wiltshire Council for more information. For contact details see section 24.
  - Carer Support Wiltshire also provides training for carers. For more details see section 24.

Looking after yourself can sometimes be hard work, but turning to your family, friends and local organisations for help is important as they can help you. You have a right to enjoy good health too.

If you do get to the point that you can not carry on caring, then you should not feel guilty or that you have let anyone down. Caring can be very rewarding, but is also exhausting and demanding. If the person you care for needs to go into residential care or hospital then remember that you have done the best that you can and that you have not failed. Your needs are just as important and sometimes this is the best solution for everyone involved.

### **Dental Services**

If you, or the person you care for need NHS dental services NHS Wiltshire's Dental Advice Line can provide information and support on how to find an NHS dentist. For more information contact the Dental Helpline – see section 24.

### **Managing your medicines**

There are various ways in which patients can be aided to take their medication. This can include reminder charts, prompts, aids to help patients take inhalers / eye drops and can also include compliance aids in the form of monitored dosing systems. These monitored dosing systems come in various forms and the most suitable one should be used. They can hold different numbers of tablets and they have various different compartments depending on need (e.g. morning, noon, evening, night). They can be bought from pharmacies for patients or carers to fill themselves. If this is to be done, it is important to ensure that the medicines are in the correct compartment of the container. There are also issues around stability of medicines when they are stored outside of their original containers – some medicines are more stable than others. This should be discussed with your pharmacist and it may be that medication may need to be discussed with the GP if a compliance aid container is to be used to ensure that medicines are as stable as they can be. A pharmacist can assess patients under the Disability Discrimination Act 1995 and can determine whether a patient would benefit from any reasonable adjustments to their services or whether an auxiliary aid would be appropriate. This auxiliary aid may be in the form of a compliance aid container.

## **Section 7 - Staying safe**

Caring for someone with dementia can mean that a lot of the time you are making sure that they are safe. This may be difficult as they may still be able to make decisions themselves, which you consider to be risky. As dementia increases, the person's ability to recognise what might be dangerous or harmful decreases. Remember, any decisions should always be made in the person's best interests.

### **Dangers in the home**

There are certain things around any home that could be a potential risk:

- Gas appliances
- Electrical equipment
- Poor lighting
- Carpets and loose rugs
- Sharp knives or hot objects
- Cleaning products and medicines

It is important to keep the person you care for away from anything that could be dangerous. If you as a carer believe that it is in the best interests of the person you care for to restrain them from harm, you are able to do so as long as it is proportionate to the risk of harm. For example, there are some things that you may be able to move out of reach, but others you cannot. You will never be able to remove all dangers, so the best you can do is to keep aware. You may want to speak to a professional for more information or refer to the Mental Capacity Act.

The Wiltshire Bobby Van provides a free home security service. They will upgrade door and window security where appropriate, e.g. locks, door chains and door viewers. They offer services such as fitting key safes (they ask for the cost of this to be covered) and will also undertake fire risk assessments, fit smoke detectors and discuss fire safety with you. For contact information, see section 24.

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 may be able to offer specialist advice and support to reduce any risks.

If the person that you look after is prone to getting lost or walking away from the house or the people they are with, then you may find it useful to ensure that an emergency number / name is placed into an item of their clothing, such as a pocket or wallet. Also, placing a mobile phone in the person's pocket or handbag would mean that they could potentially be tracked if they were judged to be at risk. You should explain to the person what is happening if you choose to take either of these actions.

## Abuse

Some people may be more at risk of being treated badly than others and there are many different reasons and situations why this occurs. Abuse is when someone tries to take away your rights, when someone does or says something to you which causes you to be unhappy, scared or angry. It can be in many different forms, such as:

- Physical abuse
- Financial abuse
- Sexual abuse
- Emotional abuse
- Neglect
- Discrimination

If you think someone is abusing you or the person you care for then it is very important that you tell someone as soon as possible. It is important to remember that if the person you care for has aggressive behaviour towards you, you should seek help as soon as possible. Likewise if you feel that you are under great strain or stress and are becoming worried that as a result you may hurt the person you care for, seek assistance as soon as possible. This should be someone you trust such as your family, a friend, a doctor, a social worker, the police or an organisation that supports you, such as Alzheimer's Society. If nothing happens after this then it is important that you tell someone different.

Wiltshire Council has the statutory responsibility for keeping people safe in Wiltshire and has a safeguarding team that you can refer to for advice. It is essential that any allegation of abuse is taken seriously however insignificant it may seem at the time.

Here are some useful contact details:

- Wiltshire Council Social Care Advisors – 0300 456 0111 – [safeguardingadults@wiltshire.gov.uk](mailto:safeguardingadults@wiltshire.gov.uk)

If you need help outside of work hours then you can contact:

- Emergency Duty Service – 0845 607 0888
- Wiltshire Police Vulnerable Adults' Unit – 01380 734212
- Police Out of Hours Service – 0845 408 7000

## **Section 8 - Relationships**

If you are caring for a person with dementia who is close to you, your relationship will change greatly as time passes. You will begin to take over a lot of the responsibilities that were previously done by the person that you care for. There may also be tasks that you start to do to help the person that you look after, which may change your relationship with them, such as assisting them to get dressed or use the toilet.

There are so many changes that occur along the way when caring for someone with dementia that it can be difficult for carers to deal with their own feelings. You may experience feelings of grief, sadness, anger, resentment and guilt. It is normal to have these feelings. Carers often find it helpful to talk through their feelings with family, friends, professionals and other people who are in a similar situation to them.

Attending support groups or seeing a counsellor may be of help. Carer Support Wiltshire or your local Alzheimer's organisation should be able to point you in the right direction. Contact details can be found in section 24.

## Section 9 - Carer Training

Whether you become a carer quickly or gradually, it can seem as though there are a lot of different things to learn. This can include learning more about what dementia is, about looking after the person you care for and looking after yourself. There is a lot of information available for you as a carer and training courses can help you find out more in an environment that is supportive and relaxed. Training can help you to face problems, look after your own health and maintain your caring role, if appropriate.

Training courses are available across Wiltshire and are delivered to small groups of carers. Many carers find these sessions very useful as they are a good place to learn new information, to be reminded of things they already knew and to share their experiences with other carers.

Different courses are available across Wiltshire and may include topics such as:

- First aid
- What is memory?
- Managing difficult behaviour
- Safe moving & handling
- Staying healthy
- Financial and legal aspects of caring
- Take care of yourself
- Stress management
- Relaxation techniques

The following organisations provide training to carers in Wiltshire:

- Carer Support Wiltshire
- Alzheimer's Society North Wiltshire
- Alzheimer's Support West Wiltshire and Kennet
- Alzheimer's Society Salisbury

Contact details can be found in section 24.

Remember you can never be too prepared, it can be good to refresh what you already know and **it is never too early to attend!**

## **Section 10 - Financial and Legal implications**

As a carer it is useful to at least have a basic understanding of the legislation that is in place to protect those with a mental illness, or those who may lack the capacity to make decisions for themselves.

### **Mental Health Act**

The Mental Health Act 2007 is designed to protect people. A person can only be detained ("sectioned") under this Act if it is felt that their health is at risk, or that they pose a risk to themselves or others. Several specified people have to agree that the Section is necessary, and there are strict guidelines about how long someone can be detained for.

### **Sections**

The Sections of the Mental Health Act that are probably most relevant for someone who has dementia are:

- Section 2: enables a person to be detained in hospital for an assessment period of up to 28 days.
- Section 3: enables a person to be detained in hospital for treatment, initially for six months. The Section may then be renewed for another six months, and after that for a year at a time.
- Section 117: requires statutory authorities to make arrangements for the continued care of a person who has been detained under Section 3. This care must be provided free of charge. An example of this would be when a person with dementia has been detained in hospital for treatment under Section 3 and is then discharged to a Nursing Home.

### **Mental Capacity Act**

The Mental Capacity Act is legislation which increases the legal rights of the person with dementia to make or be involved in decisions about their own health and care. Capacity is the ability to make a specific decision at the time it needs to be made. The Act also means that when somebody no longer has the mental capacity to make a specific decision for themselves, the decision must be made in their best interests (usually by a health or social care professional) and their carer and others involved in the person's care have the right to be consulted about each decision that needs to be made in their best interests. You can be the decision maker if you have been given a lasting power of attorney for health and welfare by the person prior to them losing the capacity to give this instruction.

The Mental Capacity Act has five principles and carers must have regard to them:

- A presumption of capacity - every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise;
- The right for individuals to be supported to make their own decisions - people must be given all appropriate help before anyone concludes that they cannot make their own decisions;
- That individuals must retain the right to make what might be seen as unwise decisions;
- Best interests - anything done for or on behalf of people without capacity must be in their best interests;
- Least restrictive intervention - anything done for or on behalf of people without capacity should be the least restrictive of their basic rights and freedoms.

Over time dementia may lead some people to lose the capacity to make some decisions about things like legal issues, finances and health affairs. It is important for all of us to plan ahead in case we are unable to take decisions for ourselves, but it is particularly important for you and the person you care for to discuss this at the early stages of the illness.

If the person you are looking after still has capacity to make financial and legal decisions **it is advised to undertake action as soon as practicable**. However, some actions may not be possible if the person is lacking this capacity and you will need to refer to the court of protection. Actions to consider taking are listed below:

### **1. 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 if they are no longer able to do so themselves.

### **2. 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 that 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 interest. You can also, in a similar way, appoint someone to make decisions about health and personal welfare. A person needs to set up a Trust to safeguard the interests of their family in the event that they can no longer do it themselves.

### **3. Lasting Power of Attorney (LPA)**

LPA is a legal document that lets you appoint someone you trust as an 'attorney' to make decisions on your behalf. This document can be drawn up at any time while you have capacity (are still mentally capable). It is useful to do this as soon as you can. You must register your LPA with the Office of the Public Guardian if your document is to have a legal standing. You can create two types of LPA:

- Property and Affairs LPA which allows you to choose someone to make decisions about how to spend your money. This can include decisions on the way your property and affairs are managed.
- Personal Welfare LPA which allows you to choose someone to make decisions about your healthcare and welfare. This includes decisions to refuse or consent to treatment on your behalf and deciding where you live. These decisions can only be taken on your behalf when the LPA is registered.

For more information have a look at [www.publicguardian.gov.uk](http://www.publicguardian.gov.uk) or ring 0300 456 0300 for more details and relevant forms.

If you already have a registered Enduring Power of Attorney for financial and property affairs, this can still be used – and it can still be registered by using the registration forms from the Office of the Public Guardian via their website [www.publicguardian.gov.uk](http://www.publicguardian.gov.uk) or by phoning them on 0300 456 0300.

### **4. Advance decisions, wishes and preferences**

As a carer, you are likely to be involved in making significant decisions for the person you care for as the impact of the dementia increases. You will be asked what the person themselves would have wanted and this will help the professionals involved reach the best possible decision - so do try and have the conversations and perhaps prepare something in writing in case of admission to hospital etc. You could do use the 'This is me' leaflet produced by Alzheimer's Society. For more information see section 5.

An advance decision is more formal and allows the opportunity for the person to refuse treatment in specific situations. You can discuss this with your GP and also can get more information from [www.adrtnhs.co.uk](http://www.adrtnhs.co.uk)

### **5. Court Appointed Deputy**

If there is not a registered LPA in place and the person you care for becomes unable to manage their financial affairs, it may be necessary to appoint a deputy through the Court of Protection, which can be an expensive option although if managing financial affairs consists simply of managing your income from benefits, it would be done through appointeeship. In some cases the court could also appoint a deputy to make health and welfare decisions if necessary.

## **6. Benefits appointee**

A carer can be named as the person's appointee so that he/she can legally handle their income from state benefits. An appointee cannot manage the person's income from other sources or their savings.

## **7. Receivership**

Receivership becomes necessary if someone who has not made a Lasting Power of Attorney becomes mentally incapable of managing their financial affairs. Acting as a receiver for someone is more complex than acting as an attorney. There are usually considerable costs involved in this process.

For any of the above actions, it is best to seek further advice. This could be from a legal professional or from an organisation such as the Citizens' Advice Bureau. For contact details see section 24.

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

This legislation is part of the Mental Capacity Act and provides protection for vulnerable people who are accommodated in hospitals or care homes in circumstances that amount to a deprivation of their liberty and who lack the capacity to consent to the care or treatment they need. These safeguards have been introduced to ensure that no one is deprived of their liberty in these care settings without good reason, that the decision is taken in their best interests and there is no less restrictive option and that people who are deprived of their liberty receive the care they need while retaining specific rights.

You as a named family member or friend may have an opinion about whether the proposed care plan is appropriate and you should be involved by the care home or hospital in this, before they apply for an authorisation. The Best Interest Assessor will also involve you in the process during the assessments. If the DoLS authorisation is granted, you may be asked if you are willing to be the Person's Representative

You may have concerns that your friend or family member is being unlawfully deprived of their liberty, in which case you should inform the hospital or care home immediately and / or discuss with the Wiltshire DoLS helpdesk team on 01225 756598.

For more information you can look at the Department of Health Website:

[www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/MentalCapacity/MentalCapacityActDeprivationSafeguards/index.htm](http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/MentalCapacity/MentalCapacityActDeprivationSafeguards/index.htm)

## **Section 11 - Benefits**

The government provides a variety of benefits for both you and the person you care for and you should not be reluctant to claim them.

If you think there is any possibility that you are not getting all the benefits to which you are entitled, we would urge you to get expert advice. This could be from Citizens Advice, the Financial Assessment & Benefits Team or your local Department of Work and Pensions. If you feel that you require assistance in accessing the benefits system as you are unsure of your entitlements, you can ask the customer advisors at Wiltshire Council for a benefits check – contact details in section 24.

### **The benefits for carers include:**

#### **Carers' Allowance**

Paid to people who spend at least 35 hours a week caring for someone. There are a large number of carers, who for various reasons are unable to claim this, but it is worth asking as you may well be able to.

#### **Carers' Premium**

If you are entitled to Income Support, income-based Jobseeker's Allowance, Pension Credit, Housing Benefit and Council Tax Benefit as a carer, you may be able to receive the carers' premium. Check with your local Benefits office or Jobcentre Plus office.

Carers caring for a total of 20 hours per week or more are also able to apply for Carer's Credit to protect their State Pension – both the basic and State Second Pension.

### **The benefits for people being cared for include:**

#### **Attendance Allowance**

Paid if you need help to look after yourself if you are aged 65 years or older

#### **Disability Living Allowance**

Paid if you need help looking after yourself before you reach the age of 65

#### **Employment Service Allowance (previously incapacity benefit)**

Paid if you are incapable of work because of sickness or disability

**Other benefits and offers that you may want to find out more about are:**

- Council tax benefit
- Housing benefit
- Income support
- Pension credit
- State retirement benefit
- Bereavement benefit
- Widow's benefit
- Winter Fuel Payment for the over 60s – call 08459 15 15 15
- Energy grants – contact Wiltshire Energy Efficiency Advice Centre (0800 512012)
- Free loft and/ or cavity wall insulation for the over 70s, call 0800 512012
- Watersure – Subject to receipt of certain prescribed benefits, this can limit water bills - 0800 169 1133

## **Section 12 - Working and caring**

The demands of caring can often lead carers to give up work, reduce their hours and limit opportunities to undertake further learning.

There are things you can do to cope with the pressures of work and care. As a working carer you are likely to need a range of support in the workplace, and often different levels of support at different times - from access to a telephone to check on the person you care for, to leave arrangements for when someone is discharged from hospital. The good news is that carers have some statutory rights and more and more employers are realising the benefits of supporting carers.

Wiltshire Council has produced a factsheet called Carers and Employment, which provides information about some of the support available for carers when considering work opportunities. For more information contact the Wiltshire Council customer advisors – details in section 24.

### **Statutory rights**

The Work and Families Act 2006 and the Employment Rights Act 1996 give working carers' rights to help them manage work and caring including the right to request flexible work and leave entitlement.

For more information or advice about your statutory employment rights call CarersLine on 0808 808 7777.

### **Talking to your employer**

Talking to your employer may help you explain the impact that caring has on your life and your job and help your employer to understand how they can best help.

Caring for a disabled relative is often unpredictable and care arrangements can be complex, so you will need to talk to your employer about your concerns and commitments.

Think about how your employer could best help you and talk to them about your needs.

If you want to work, it is in your employer's best interest to consider making reasonable changes to your work pattern to help you work and continue caring.

Many employers offer help to carers. This could include:

- talking to a welfare officer or occupational health adviser who knows about carers
- in-house information and advice or counselling
- a subscription to a carers' organisation, or employee services

## **Returning to work**

There are a number of recent developments which can help carers stay in work or return to work, including flexible working arrangements and financial support for some carers. This includes New Deal and the Education Maintenance Allowance which can help young carers to continue to study. City and Guilds has worked with Carers UK, Action for Carers and Employment (ACE) National and other partners to develop "Learning for Living", personal development and learning tools for carers. Learning for Living consists of online learning resources for carers and a qualification.

JobCentre Plus have specialist advisors who can help you as a carer who wants to work, including financial help for funding replacement care whilst accessing JobCentre Plus programmes and services. For more information, call your local JobCentre Plus office.

## **Working carers' groups**

Carer Support Wiltshire runs a working carers groups, which allow carers who work and balance a caring role to get together, socialise and share experiences. Contact details in section 24.

## Section 13 - Hospitals and discharge

One of the areas that many carers find difficult is when the person they care for has been in hospital and is then discharged. The reasons for this can vary, but often involve the changes in the health and care needs of the person you look after.

During the cared for person's stay in hospital there will be 'family meetings' (which also include carers who are not family), where discharge arrangements are discussed. It is extremely helpful for as much information about the cared for person's home circumstances to be available as soon as possible in order to make the correct choices/decisions for discharge planning.

Do not hesitate to ask questions or provide further information either when you visit or phone the hospital.

Before a patient is able to leave hospital, a discharge plan should be prepared by the hospital with you and the person you care for. If there are doubts concerning the capacity of the person you care for to make any decisions about their future care and/or treatment, then a mental capacity assessment must take place. If following the assessment, it is judged that the person does not have the capacity to understand the decision they need to make, and is unable to weigh up the risks and consequences of making that decision, then a best interests meeting will be held to which you should be invited.

The care plan will normally include:

- details of the staff member who is responsible for discharge.
- details of any help, support and equipment which need to be arranged.
- contact details of any community health services that will be involved.

Social care staff can provide information about services available and provide details of other organisations where appropriate.

Whilst hospitals will be making sure that everything goes as well as possible, you may find it useful to use the checklist below to make sure that the right plans are in place for when the person you care for is discharged.

- Has the person you care for been given at least 24 hours notice before being discharged?
- Has any transport that is needed been organised?
- Has any property and valuable items been returned to the person you care for?
- Has any equipment, training or fittings been supplied to where the person will be returning to?
- Do you know what care will be provided to the person you look after when they return home and have you been involved in these decisions?
- Has someone talked to you about the level and type of care that you will be providing and whether you are happy and able to provide this?

- Has the person's GP been told that they are being discharged?
- Have any medicines that are needed been supplied? Do you know how many the person needs to take and any side effects?
- Have any medicines been put into a dosage box before the person leaves the hospital?
- Have you got information about the person's health condition, what symptoms to look for and how to get help if you need it?
- Do you know what follow up health appointments are needed?

You may well think of other questions to add to this list – this is just a starting point. Make sure that you speak to the people in the hospital if you have any concerns, and remember that there is no such thing as a silly question. As the main carer it is important that you know what is happening and you should not be afraid to ask.

## **Section 14 - Working with professionals**

It is likely that you are the person who knows the most about the person you care for. Sometimes professionals can forget this and they may try and make decisions without taking your caring role into consideration. This can sometimes feel like they are taking over and not involving you in decisions, which will have a big impact on you and the person that you care for.

If however you have a Lasting Power of Attorney for health and well being you have the legal rights to be the decision maker in these situations. The Mental Capacity Act tells professionals that they must consult with you as a carer whenever they have to make decisions and so you could remind them of your legal rights to be involved. The decision makers need to listen to what you think is in the best interests of the person you care for and your reasons for thinking this (e.g. because you are the one who knows what the person would have preferred to happen to them) – but they may have a different opinion and you can make a challenge to this legally.

It is important to remember that you are the carer and that your role is vital. You may have to remind the professionals involved that you are a partner in caring for the person with dementia and that without you, they would not be able to do their job. You should not be worried about saying this, if it is in the best interest of those involved. If you feel unable to do this, then there are advocacy services available in Wiltshire who will help you to voice your issues and concerns. Contact details for SWAN Advocacy can be found in section 24.

You may also find it useful to ask the professionals that they share information with you about the person you care for. They may have to ask the consent of the person with dementia to do this. Given the nature of dementia, many people may find this useful to do early on as it can ensure that you stay informed about their health and care.

## **Section 15 - Telecare**

Telecare is sometimes called assistive technology. It aims to promote people's independence, improve safety at home and provide reassurance to people and those who care for them.

It usually consists of a base unit, linked to a telephone and a personal pendant that is worn around the neck, on the wrist or attached to a belt. There are also a number of sensors that automatically monitor the home environment. These are linked to the base unit without the need for wiring and can detect potential dangers such as gas, extreme temperatures, smoke or overflowing water.

When the alarm is activated, trained staff at a monitoring centre will respond and, if necessary, will arrange for someone to visit at any time of the day or night. They may also contact the emergency services if necessary.

If you are interested in telecare and think that this may be a useful addition to the support available to the person that you care for, you can get further information about the options available in your area from the customer advisors at Wiltshire Council – contact details in section 24.

## **Section 16 - Sheltered housing**

Sheltered housing covers a wide range of supported housing for people. It is important therefore to check what facilities a particular sheltered housing scheme will offer.

It is rented or owner occupied accommodation and the majority have a scheme manager or warden and a community alarm service. The scheme manager may be on site or shared between a number of schemes. They do not offer personal care but offer low-level support including emergency support often through a linked alarm system. They also help older people obtain the care and support they need and the support they offer includes things like help with form filling, general safety checks and enabling residents to organise or access other facilities and services. Some schemes have communal facilities such as a common room, laundry, guestroom and gardens and some will include a restaurant and the provision of hot meals.

## **Section 17 - Extra care housing**

Extra care housing is a growing part of the housing market for people. It can be owned, rented, part owned/rented (shared ownership) or leasehold. Extra care housing can broadly be described as housing into which a range of care and support services can be delivered on-site 24 hours a day.

Extra care is gaining a reputation for offering accommodation and care to people who would otherwise be frequent users of acute services (largely because they cannot look after themselves in unsuitable housing). Models of extra care are various, because it is a concept rather than a housing type.

Generally however, an extra care scheme is a development of flats and/or bungalows with a manager and the availability of care and support to tenants/leaseholders 24 hours a day, usually supported by a lifeline and other technological assistance. There is normally a café or meal provision available and an additional range of services and activities which are open to tenants/leaseholders and others living in the surrounding area.

## **Section 18 - 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 that they can remain as independent as possible. This can also help you as a carer, as it can reduce the number of additional tasks that you have to do.

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.

This help from domiciliary care services 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. The person you care for will be financially assessed to see if they will need to make a financial contribution towards the cost of any services.

The service is provided by an independent company and funded by social services within certain financial guide lines.

To access information regarding domiciliary care in Wiltshire you can call the customer advisors at Wiltshire Council - contact details in section 24.

Domiciliary care can also be arranged by contacting your doctor, hospital, social worker or key worker / care manager.

## **Section 19 - Residential care**

Some carers decide that they will try to continue looking after the cared for person in the home environment.

In many carers' lives however, there comes a time when they realise that, despite how hard they try they can no longer provide the care needed for the person in their own home. The ability of the person you are caring for to make a decision about their future care and accommodation needs to be assessed and only if they lack the ability to make this decision can a best interests decision be made on their behalf. You can ask a health or social care worker to carry out this assessment regardless as to whether funding is needed to pay for alternative care.

If, following a capacity assessment, a best interests decision has been made that the person you care for should move to an alternative care setting, you will be given advice as to the type of care home that should be considered. This will largely depend upon the health and / or the behavioural traits of the person that you look after.

To place the person you care for into a home might feel very difficult. One cannot prepare for the feelings of loss, failure, guilt, and lack of purpose that you might find come flooding to the surface.

Many carers find this step to be the most painful and difficult to take. 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. If the person does not understand that they need to remain in the particular care home in order to receive the care and treatment they need, the home may request an authorisation for Deprivation of Liberty Safeguards so that they can, in the person's best interests, ensure that the person cannot leave the home at will. In these circumstances, you would be asked to act as a personal representative and be given the power to ask for reviews etc. on the person's behalf.

There are two 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.
- **Nursing Care Home**  
Provides care for people with more 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.

Both types of care homes might provide care for people with mild to moderate dementia. In addition some care homes provide care for people whose needs require more specialist input where the staff have the experience and skills to cope with more challenging behaviours. These care homes may have specialist dementia units or the home may specialise in dementia care. This used to be referred to as Elderly Mentally Infirm (EMI). Some care homes similarly specialise in providing care for people with specific mental health needs.

Do not feel pressurised or hurried into moving the cared for person. Take advice on the care homes and visit as many as you wish before choosing one.

If you have a care manager / key worker then they will have a list of care homes that are registered with the Care Quality Commission (CQC) in the area and will assist you in this step. If not, more information can be found out by contacting the Care Quality Commission or Wiltshire Council.

To be registered, all care homes have to be inspected by the Care Quality Commission (CQC) and you can ask the home for a copy of their latest report. Otherwise, if you have access to the internet you will be able to find the latest inspection reports for any particular care home at [www.cqc.org.uk/findcareservices.cfm](http://www.cqc.org.uk/findcareservices.cfm) , or you can contact Wiltshire Council (in section 24 for details) for more information. The CQC website also has useful information about what to think about when choosing a care home and some examples of good and bad practice to help you.

As the carer you have become the voice of the person that you look after 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 – you can call one of the Wiltshire Council customer advisors. For contact details see section 24.

Ask to be assessed for continuing health care (NHS funding for a package of care) if the cared for person is very ill. This is where your record of medical treatment and incidents will serve you well.

Again do not feel pressurised or hurried into a decision before you understand all the financial implications of the move.

Choose your care home very carefully. Make sure it will be able to meet the needs of the individual that you care for.

## **Section 20 - Counselling**

Counselling is a talking therapy that gives people the chance to talk in confidence to a trained professional about problems or issues that are causing them concern. There are many different types of counselling available.

Counselling consists of an agreed number of regular sessions between a counsellor or therapist and the person seeking support, often called the 'client'. Sessions usually last for an hour, but they can be shorter. Counselling can last for a few weeks, several months or even years. The counsellor listens to the person's concerns in a non-judgmental and supportive manner. Together, the counsellor and the client try to find ways for the client to cope and/or feel better about themselves and their situation. This may result in a more satisfying and manageable life.

The relationship between client and counsellor is confidential. This means what is discussed at the sessions will not be disclosed to anyone else. Some of the issues that the client will bring to the session may be distressing or embarrassing. This is normal. Sharing these feelings and thoughts in a supportive, safe and confidential setting is often helpful, and can be life changing.

Counselling can increase feelings of self-worth, well-being and capability, and help ease feelings of depression, anxiety, loss of control and sleeplessness.

Counselling can be very beneficial for the person who is experiencing dementia and for you, if you are caring for someone with dementia. Caring for someone with dementia can be a very lonely time, and can be overwhelming. Many carers experience feelings of sadness, guilt, anger and grief, and talking through these feelings with an experienced counsellor can help you to explore and understand your thoughts.

Alzheimer's Support provide a free counselling service for carers of people with dementia who live in West Wiltshire. More details of this can be found in section 24.

Other organisations also offer counselling or will point you in the right direction, such as the Samaritans, Cruse and the Citizens' Advice Bureau. Contact details in section 24.

Counselling services and other psychological therapies are available from the NHS, speak to your GP.

## **Section 21 - Wiltshire Council Factsheets**

Wiltshire Council factsheets cover a wide range of information about services in Wiltshire. They can be found at

[www.wiltshire.gov.uk/adultcarefactsheets.htm](http://www.wiltshire.gov.uk/adultcarefactsheets.htm) or you can call 0300 456 0111.

- 1 Assessment of Need
- 2 Eligibility Criteria and Fair Access to Care
- 3 Residential/Nursing Home Care
- 4 Residential/Nursing Home Fees
- 5 Domiciliary Care
- 6 Direct Payments
- 7 Protecting (Safeguarding) Vulnerable Adults from Abuse
- 8 Social Care Help Desk
- 10 Day Services for People with a Learning Disability
- 11 Advocacy
- 12 Adult Placement
- 13 Community Meals
- 14 Re-Ablement Service
- 19 Supporting People
- 20 Homeshare
- 22 Charges and Benefits
- 23 Management of Personal Financial Affairs
- 24 Registering Disabled (Chronically Sick & Disabled Persons Act)
- 25 NHS Funded Nursing Care
- 26 Changes to rates for NHS Funded Nursing Care

## **Section 22 - Alzheimer's Society Factsheets**

Alzheimer's Society factsheets cover a wide range of dementia-related topics. They can be found at [www.alzheimers.org.uk/factsheets](http://www.alzheimers.org.uk/factsheets) or by contacting 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 (DLB)?
- 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 used 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

### **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 The 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 everyday 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

#### **Health and social care**

- 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 Benefits 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
- 468 Paying care home fees
- 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

## Section 23 - Age UK Factsheets

Age Concern's factsheets cover a wide range of topics. They can be found at [www.ageuk.org.uk/publications](http://www.ageuk.org.uk/publications) or by contacting 0800 169 6565.

- 1 Help with heating
- 2 Buying retirement housing
- 3 Television licence concessions
- 4 Your rights at work
- 5 Dental care: NHS and private treatment
- 6 Finding help at home
- 7 Making a Will
- 8 Council and housing association housing
- 9 Anti-social behaviour in housing
- 10 Paying for permanent residential care
- 11 Help with looking for work or starting your own business
- 13 Funding repairs, improvements and adaptations
- 14 Dealing with an estate
- 15 Income Tax
- 17 Housing Benefit and Council Tax Benefit
- 19 The State Pension
- 20 NHS continuing health care, NHS-funded nursing care and intermediate care
- 21 Council Tax
- 22 Arranging for others to make decisions about your finances or welfare
- 23 Help with continence
- 24 Self directed support: direct payments, personal budgets and individual budgets
- 26 Public transport and concessions
- 27 Planning for a funeral
- 29 Finding care home accommodation
- 30 Leisure and learning
- 32 Disability and ageing: your rights to social services
- 33 Crime prevention for older people
- 34 Attendance Allowance
- 35 Tenants' rights - rents
- 37 Hospital discharge arrangements
- 38 Treatment of property in the means test for permanent care home provision
- 39 Paying for care in a care home if you have a partner
- 40 Deprivation of assets in the means test for care home provision
- 41 Local authority assessment for community care services
- 42 Disability equipment and how to get it
- 43 Getting legal advice
- 44 local NHS services
- 45 Staying healthy in later life
- 46 Paying for care and support at home
- 48 Pension Credit
- 49 The Social Fund
- 50 Housing choices

52	Disability Living Allowance
53	Capital, income and means-tested benefits
55	Carer's Allowance
56	Benefits for people under State Pension age
58	Paying for temporary care in a care home
59	How to resolve problems and make a complaint about a local authority
60	Choice of accommodation - care homes
61	Help with health costs
62	Deprivation of Liberty Safeguards
63	Finding private rented accommodation
64	Retirement (sheltered) housing
65	Equity release
66	Resolving problems and making a complaint about NHS care
67	Tenants' rights - repairs
68	Tenants' rights - security of tenure
69	Water advice
70	dealing with disputes at work
71	Park Homes
72	Advance decisions, advance statements and living wills
73	Driving and parking
74	How to challenge a benefits decision
75	Debt management
76	Immediate Care
77	The law on age discrimination
78	Safeguarding older people from abuse

## Section 24 - Contact details

Organisation	Contact details
Age UK (previously Age Concern and Help the Aged)	Tel: 0800 169 6565 Website: <a href="http://www.ageuk.org.uk">www.ageuk.org.uk</a>
Alzheimer's Society – North Wiltshire	Tel: 01249 443469 Website: <a href="http://www.alzheimers.org.uk">www.alzheimers.org.uk</a>
Alzheimer's Society Salisbury	Tel: 01722 326236 Website: <a href="http://www.alzheimers.org.uk">www.alzheimers.org.uk</a>
Alzheimer's Support West Wiltshire and Kennet	Tel: 01225 776481 Website: <a href="http://www.alzheimerswiltshire.org.uk">www.alzheimerswiltshire.org.uk</a>
Alzheimer's Society (National)	Tel: 0207 423 3500 Website: <a href="http://www.alzheimers.org.uk">www.alzheimers.org.uk</a>
Benefits Team –Wiltshire Council	Tel: 0300 456 0111
Blue Badge Parking Scheme	Tel: 01225 713002 Website: <a href="http://www.wiltshire.gov.uk/bluebadges">www.wiltshire.gov.uk/bluebadges</a>
British Red Cross	Tel: 0844 871 1111 Website: <a href="http://www.redcross.org.uk">www.redcross.org.uk</a>
Carer Support Wiltshire  (Previously: Carer Support West Wilts, Carer Support North Wilts, Carers Support Kennet and Carers Support South Wiltshire)	West Wiltshire/main office - Tel: 01380 871690 North Wiltshire -Tel: 01249 444110 East Wiltshire - Tel: 01672 564265 South Wiltshire - Tel: 01722 322746  Website: <a href="http://www.carersinwiltshire.co.uk">www.carersinwiltshire.co.uk</a>
Carers Emergency Card	Tel: 0800 066 5068
Carers UK	Tel: 0207 378 4999 Website: <a href="http://www.carersuk.org">www.carersuk.org</a>
Carers Direct	Tel: 0808 802 0202 Website: <a href="http://www.nhs.uk/Carersdirect">www.nhs.uk/Carersdirect</a>
Citizens Advice Bureau - Kennet	Tel: 01380 728771 Website: <a href="http://www.cabwiltshire.org.uk">www.cabwiltshire.org.uk</a>
Citizens Advice Bureau – North Wiltshire	Tel: 0845 120 3707 Website: <a href="http://www.northwiltscab.org.uk">www.northwiltscab.org.uk</a>
Citizens Advice Bureau – West Wiltshire Wide	Tel: 0844 499 4106 Website: <a href="http://www.cabwiltshire.org.uk">www.cabwiltshire.org.uk</a>
Citizens Advice Bureau – Salisbury and District	Tel: 01722 327222 Website: <a href="http://www.cabsalisbury.org.uk">www.cabsalisbury.org.uk</a>
Care Quality Commission	Tel: 0300 061 6161 Website: <a href="http://www.cqc.org.uk">www.cqc.org.uk</a>
Community Mental Health Teams for Older People, Avon and Wiltshire Mental Health Partnership	Tel: North Wiltshire - 01249 707 971 Tel: Kennet - 01380 731 358 Tel: Trowbridge - 01225 356 400 Tel: Warminster and Westbury - 01985 220 035 Tel: Salisbury – 01722 820252 Website: <a href="http://www.awp.nhs.uk">www.awp.nhs.uk</a>
Community Transport	Tel: 01380 722475 Website: <a href="http://www.wiltshirecommunitytransport.org.uk">www.wiltshirecommunitytransport.org.uk</a>
Consumer Direct	Tel: 0845 404 0506 Website: <a href="http://www.consumerdirect.gov.uk">www.consumerdirect.gov.uk</a>

<b>Organisation</b>	<b>Contact details</b>
Counsel and Care	Tel: 0845 300 7585 Website: <a href="http://www.counselandcare.org.uk">www.counselandcare.org.uk</a>
Cruse	Tel: 0844 477 9400 Website: <a href="http://www.crusebereavementcare.org.uk">www.crusebereavementcare.org.uk</a>
Dental NHS Dental Helpline	Tel: 0845 758 1926 Website: <a href="http://www.wiltshirepct.nhs.uk/DentalService">www.wiltshirepct.nhs.uk/DentalService</a>
Great Western Ambulance Service Headquarter	Tel: 01249 858500 Website: <a href="http://www.wiltsamb.nhs.uk">www.wiltsamb.nhs.uk</a>
Health – NHS Wiltshire	Tel: 0800 389 7671 Website: <a href="http://www.wiltshirepct.nhs.uk">www.wiltshirepct.nhs.uk</a>
Hospital - Chippenham	Tel: 01249 447100
Hospital - Devizes	Tel: 01380 723511
Hospital - Great Western Hospital	Tel: 01793 604020 Website: <a href="http://www.swindon-marlborough.nhs.uk">www.swindon-marlborough.nhs.uk</a>
Hospital- Royal United Hospital	Tel: 01225 428331 Website: <a href="http://www.ruh.nhs.uk">www.ruh.nhs.uk</a>
Hospital - Salisbury	Tel: 01722 336262 Website: <a href="http://www.salisbury.nhs.uk">www.salisbury.nhs.uk</a>
Hospital - Trowbridge	Tel: 01225 711300
Independent Complaints Advocacy Service (NHS complaints only)	Tel: 01225 762723 Website: <a href="http://www.seap.org.uk/icas">www.seap.org.uk/icas</a>
Mencap	Tel: 0207 454 0454 Website: <a href="http://www.mencap.org.uk">www.mencap.org.uk</a>
Mind	Tel: 01225 775770 Website: <a href="http://www.wiltshiremind.co.uk">www.wiltshiremind.co.uk</a>
NHS Direct	Tel: 0845 4647 Website: <a href="http://www.nhsdirect.nhs.uk">www.nhsdirect.nhs.uk</a>
Royal National Institute for Deaf People	Tel: 0207 296 8000 Website: <a href="http://www.rnid.org.uk">www.rnid.org.uk</a>
Royal National Institute for the Blind	Tel: 0303 123 9999 Website: <a href="http://www.rnib.org.uk">www.rnib.org.uk</a>
Princess Royal Trust for Carers	Tel: 0844 800 4361 Website: <a href="http://www.carers.org">www.carers.org</a>
Samaritans	Tel: 0845 790 9090 Website: <a href="http://www.samaritans.org">www.samaritans.org</a>
Stroke Association	Tel: 0845 303 3100 Website: <a href="http://www.stroke.org.uk">www.stroke.org.uk</a>
SWAN Advocacy	Tel: 01722 341851 Website: <a href="http://www.swanadvocacy.org.uk">www.swanadvocacy.org.uk</a>
Vitalise	Tel: 0845 345 1972 Website: <a href="http://www.vitalise.org.uk">www.vitalise.org.uk</a>
Wiltshire Bobby Van	Tel: 01225 794652 Website: <a href="http://www.wiltshirebobbyvan.org.uk">www.wiltshirebobbyvan.org.uk</a>
Wiltshire Council customer advisors – Adult Care	Tel: 0300 456 0111 Website: <a href="http://www.wiltshire.gov.uk">www.wiltshire.gov.uk</a>
Wiltshire Council Libraries	Tel: 0300 456 0100 Website: <a href="http://www.wiltshire.gov.uk/libraries">www.wiltshire.gov.uk/libraries</a>

Organisation	Contact details
Wiltshire DoLS helpdesk team	Tel: 01225 756598
Wiltshire Police	Tel: 0845 408 7000 Website: <a href="http://www.wiltshire.police.uk">www.wiltshire.police.uk</a>
Young Carers – Youth Action Wiltshire	Tel: 01380 720671 Website: <a href="http://www.youthactionwiltshire.org">www.youthactionwiltshire.org</a>

















## Section 28 - Emergencies

Place this near your telephone or on your fridge door.

### Carers Emergency Card

My Carers Emergency Card Number is ..... Please call 0800 066 5409 and quote my number. (To find out more see section 5.)

### Emergency Details of Cared for Person

Name	
Address	
Post Code	
Telephone Number	

### Emergency contact details

REMEMBER IN AN EMERGENCY YOU SHOULD CALL 999 FIRST

These are the people you know who should be contacted if there is an emergency.

Details	Person 1	Person 2
Name		
Relationship		
Home telephone		
Work telephone		
Mobile telephone		

### List of prescribed medication per day for the person I care for

Name of medication	Strength	Quantity	Times per day

### Any other relevant or useful information, including any allergies

--

## Section 29 - How to make a complaint, comment or compliment

When you become a carer you may come in to contact with a lot of different organisations. We hope that your experience will be a positive one, but this may not always be the case.

Organisations want to hear about what you think about their services, whether it be good or bad, as it will help them to improve the way that they work and plan for the future.

All organisations in Wiltshire should have a formal way to make complaints, comments or compliments. If you would like to make one of these, you can contact the organisation directly (details in section 24).

For some organisations in Wiltshire there are specific ways to make a complaint, comment or compliment and these are listed below:

Organisation	Contact details
Department of Community Services, Wiltshire Council	Tel: 0300 456 0111 Email: <a href="mailto:customeradvisors@wiltshire.gov.uk">customeradvisors@wiltshire.gov.uk</a> Address: Department of Community Services, Wiltshire Council, Bythesea Road, Trowbridge, BA14 8JN
Avon and Wiltshire Mental Health Partnership Trust	Tel: 01249 468 217 Email: <a href="mailto:complaints@awp.nhs.uk">complaints@awp.nhs.uk</a> Address: Complaints, Jenner House, Langley Park, Chippenham, SN15 1GG
NHS Wiltshire	Tel: 0800 389 7671 Email: <a href="mailto:pals@wiltshire.nhs.uk">pals@wiltshire.nhs.uk</a> Address: PALS Manager, Wiltshire Primary Care Trust Southgate House, Pans Lane, Devizes, SN10 5EQ
Royal United Hospital	Tel: 01225 825 656 Email: <a href="mailto:pals@ruh.nhs.uk">pals@ruh.nhs.uk</a> Address: Head of PALS, RUH Bath NHS Trust Combe Park, Bath, BA1 3NG
Great Western Hospital	Tel: 01793 604 020 Email: <a href="mailto:pals.team@gwh.nhs.uk">pals.team@gwh.nhs.uk</a> Address: PALS Office, Great Western Hospitals NHS Foundation Trust, Great Western Hospital, Marlborough Road, Swindon SN3 6BB
Salisbury District Hospital	Tel: 0800 374208 Email: <a href="mailto:customercare@salisbury.nhs.uk">customercare@salisbury.nhs.uk</a> Address: The Chief Executive, Salisbury NHS Foundation Trust, Trust Offices, Salisbury District Hospital, Salisbury Wiltshire SP2 8BJ
Avon & Wiltshire Mental Health Trust (responsible for community mental health teams)	Tel: 0800 073 1778 Email: <a href="mailto:pals@awp.nhs.uk">pals@awp.nhs.uk</a> Address: PALS Office, Avon and Wiltshire Mental Health Partnership NHS Trust, Jenner House, Langley Park Estate, Chippenham, SN15 1GG

<b>Organisation</b>	<b>Contact details</b>
Great Western Ambulance Service Headquarters	Tel: 01249 858 500 Email: <a href="mailto:pals@gwas.nhs.uk">pals@gwas.nhs.uk</a> Address: PALS, Great Western Ambulance Service NHS Trust, Head Office, Jenner House, Langley Park, Chippenham SN15 1GG

Information about Wiltshire Council services can be made available on request in other languages including BSL and formats such as large print and audio.

Please contact the council by telephone 0300 456 0100, by textphone 01225 712500, or email [customerservices@wiltshire.gov.uk](mailto:customerservices@wiltshire.gov.uk)

يمكن، عند الطلب، الحصول على معلومات حول خدمات مجلس بلدية ويلتشير وذلك بأشكال (معلومات بخط عريض أو سماعية) ولغات مختلفة. الرجاء الاتصال بمجلس البلدية على الرقم ٠٣٠٠٤٥٦٠١٠٠ أو من خلال الاتصال النصي (تيكست فون) على الرقم ٧١٢٥٠٠ (٠١٢٢٥) أو بالبريد الإلكتروني على العنوان التالي: [customerservices@wiltshire.gov.uk](mailto:customerservices@wiltshire.gov.uk)

如果有需要我們可以使用其他形式（例如：大字體版本或者錄音帶）或其他語言版本向您提供有關威爾特郡政務會各項服務的資訊，敬請與政務會聯繫，電話：0300 456 0100，文本電話：(01225) 712500，或者發電子郵件至：[customerservices@wiltshire.gov.uk](mailto:customerservices@wiltshire.gov.uk)

Na życzenie udostępniamy informacje na temat usług oferowanych przez władze samorządowe hrabstwa Wiltshire (Wiltshire Council) w innych formatach (takich jak dużym drukiem lub w wersji audio) i w innych językach. Prosimy skontaktować się z władzami samorządowymi pod numerem telefonu 0300 456 0100 lub telefonu tekstowego (01225) 712500 bądź za pośrednictwem poczty elektronicznej na adres: [customerservices@wiltshire.gov.uk](mailto:customerservices@wiltshire.gov.uk)

ولشائر کونسل (Wiltshire Council) کی سروسز کے بارے میں معلومات دوسری طرزوں میں فراہم کی جاسکتی ہیں (جیسے کہ بڑی چھپائی یا آڈیو ہے) اور درخواست کرنے پر دوسری زبانوں میں فراہم کی جاسکتی ہیں۔ براہ کرم کونسل سے 0300 456 0100 پر رابطہ کریں، ٹیکسٹ فون سے (01225) 712500 پر رابطہ کریں یا [customerservices@wiltshire.gov.uk](mailto:customerservices@wiltshire.gov.uk) پر ای میل بھیجیں۔