

2015



Living with dementia



In Walsall



Walsall Council



Walsall Clinical Commissioning Group

Content Page

Section 1: A diagnosis of dementia Page 3

Emotional support Page 3

More about dementia Page 4

Section 2: How will dementia affect me? Page 6

Section 3: What can I do to help myself? Page 8

Section 4: Practical help Page 16

Section 5: Planning for the future Page 27

Section 6: Further information Page 42

Section 7: Frequently asked questions (FAQs) Page 48

Section 8: Feedback form Page 53



Living with dementia

This is a guide for people who have been diagnosed with dementia. A diagnosis of dementia is usually given by the Memory Assessment Service following a referral from your GP and after an assessment. Some people however, are diagnosed by a neurologist, physician or by a community mental health team.

Whilst you may have been diagnosed and given the name of a particular sub-type of dementia, such as Alzheimer's disease or Vascular dementia, this guide is for any type of dementia.

The guide has been written to give you information about dementia, how it is likely to affect you, what you can do to help yourself and where you can get help from other people. Understanding more about dementia can reduce some of the anxieties you may have and help you to plan for the future.

Section 1:

A diagnosis of dementia

Although dementia is a condition which gradually gets worse, it does not mean that you cannot lead an enjoyable life or that you will suddenly have to move into a care home or be dependent on others. People have dementia over a period of years and can still have an active and enjoyable life. You are the same person you were before you received the diagnosis of dementia.



How fast dementia progresses will depend on the individual. Each person is different, so no two people with dementia will experience it in the same way. The important thing is that you are not alone and you are not helpless. There are people to help and support you.

Emotional support

People react differently to being diagnosed with dementia. It is perfectly normal to feel shock, fear or anger; and even all three. Some people may prefer to keep the diagnosis private but it is good to talk to people you trust. This could be your family, friends, GP or even the memory service staff who diagnosed you.

Give yourself time to come to terms with the diagnosis. This will help. You might find it useful to make a list of questions, particularly if there is something you are unsure of or want to know more about.

Reading this guide with someone else may be helpful. It might help clarify things for you but also inform the people you know about dementia.

If you are reading this guide but do not have a diagnosis of dementia, please read the “Are you worried about your memory” guide, which will help you if you are concerned you might have dementia.

More about dementia

The word 'dementia' is used to describe a group of symptoms that occur when the brain is affected by specific diseases and conditions. The most common dementias are:

Alzheimer's disease

A German neurologist called Alois Alzheimer discovered 'plaques' and 'tangles' which had developed in the structure of the brain and resulted in brain cell death. When this happens, atrophy or shrinkage can usually be seen on brain scans. People with Alzheimer's disease are also believed to have a shortage of some brain chemicals, which are responsible for the transmission of messages around the brain.



Vascular dementia

Brains cells need a good supply of blood to remain healthy. The blood supply is called the vascular system. In vascular dementia, this supply can be cut off and lead to the death of brain cells. There are two main types of vascular dementia; one caused by stroke and the other by small vessel disease.

Strokes are interruptions to the blood supply of the brain causing permanent damage. The part of the brain the stroke is in makes a difference to the symptoms people have. A

single stroke is known as single infarct dementia and several strokes are known as multi-infarct dementia. Multi-infarcts can be very small and barely noticeable to people.

The second type is small vessel disease which is caused by damage to tiny blood vessels deep in the brain. These symptoms tend to occur more gradually.

The vascular system can be damaged or made worse by high blood pressure, high cholesterol, diabetes and heart disease so it is important to identify and treat these conditions as early as possible.

Mixed dementias

Mixed dementia means having more than one type of dementia, e.g. both Alzheimer's disease and a vascular dementia.

Lewy Body dementia

Fredrick Lewy identified abnormal, tiny, spherical protein deposits in brain cells. These are known as Lewy bodies. They are believed to interrupt important chemical messengers in the brain. People with Alzheimer's disease and Parkinson's disease can also have these Lewy bodies present and therefore can share similar symptoms. This can make a diagnosis of Lewy body dementia more difficult. It is not known exactly why Lewy bodies occur.

Dementia in Parkinson's disease

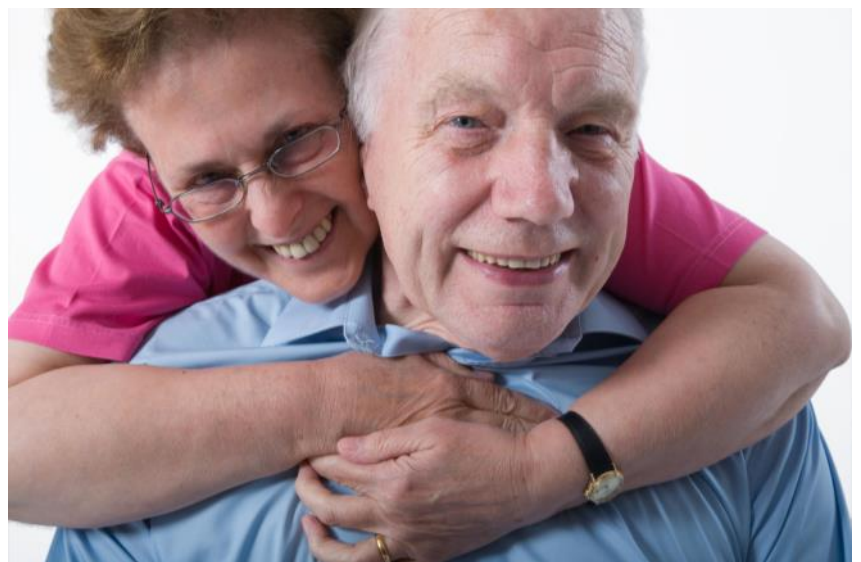
The causes of dementia in Parkinson's disease are not yet fully understood. People who have dementia in Parkinson's disease have been found to have Lewy bodies in their brain and there are similarities with Lewy body dementia. This affects about 15-30% of people diagnosed with Parkinson's disease.

Fronto-temporal dementia

People diagnosed with Fronto-temporal dementia were originally said to have Pick's disease. Pick's disease was identified by Alois Alzheimer and named after his colleague and friend Arnold Pick, who had studied people with this disease.

Fronto-temporal dementia actually covers several conditions: Picks disease, frontal lobe degeneration and dementia associated with Motor neurone disease. All of these conditions cause damage to the frontal and temporal lobes of the brain. It is a less common form of dementia and often seen in younger people (under 65). Fronto-temporal dementia affects language skills, emotional responses and behaviour.

Whilst these types of dementia have slightly different presentations and can affect people in different ways, there are similar difficulties that people with dementia experience. The section below describes these.



Section 2: How will dementia affect me?

Dementia affects people in different ways. Everyone will experience dementia in their own way and no two people will be affected in the same way. However, there are signs and symptoms which are helpful to mention and these are listed below.

The important thing is that you will need time to come to terms with a diagnosis of dementia. Having information about dementia early on will give you the opportunity to make changes in your life and plan for the future. Informing those people you are closest to about your diagnosis will give you the opportunity to share any concerns you have and give your friends and family the opportunity to help you make the necessary adjustments and plans for your future.

The early symptoms of dementia you will probably already be familiar with. They include short term memory problems, such as remembering dates, what day it is, people's names or forgetting appointments. Problems with language are also very common. This includes remembering the names of objects, forgetting what words you want to use or finding that you substitute words when you cannot remember the word you wanted to use. You may find that you cannot finish a sentence or lose track of a conversation. All of this can be very frustrating and quite irritating at times for the person with dementia.



To other people you might appear confused at times as you spend longer thinking about things or responding to questions; particularly when you cannot find the answer. Try not to worry or become embarrassed by this. Many people have found that simply telling other people that you have dementia makes it much easier for both you and them in understanding how dementia will affect you. Certainly your family and friends will notice these changes in you and they will be aware of any changes in your personality or behaviour. Sometimes it is helpful to ask your GP or memory service to talk to your family, so they have more information about how dementia will affect you.

As time goes on you will find remembering things increasingly difficult and thinking problems through will become more of an issue. This includes taking in new information, making decisions and even reading and writing.

Later you will find everyday activities increasingly difficult. This includes tasks like shopping, attending appointments, paying bills, preparing food, cooking and managing money. Eventually you may need help with washing, dressing and ensuring you get enough to eat and drink.



Whilst this will all seem quite frightening for you now, the deterioration described above is usually over a period of years. Indeed some people stay the same for months without any obvious changes. Most people have had dementia for quite some time before they receive a diagnosis and whilst they have often been aware of problems, have managed to function quite well with the help of family and friends.

Because short term memory is usually affected in the early stages of dementia, some people find themselves feeling that they have better long term memory and enjoy reminiscing about the past. It may be that you re-discover and get enjoyment from old family photographs or other activities you have previously enjoyed like music or gardening.

Section 3: What can I do to help myself?

The good news is that there are many things you can do to help yourself and help maintain your independence for as long as possible. The changes described above are not sudden changes but changes that occur gradually and often over a period of years. Making changes to your lifestyle may help you to adjust to these changes more easily. There are some people who can advise and support you.

Personal Assistants: Dementia

The Personal Assistants for dementia which you may hear referred to as 'PADs' are a new service who should be in post by September 2015. All newly diagnosed people will be referred to this support service if they wish.

Dementia Support Worker: Screening and Support

Support people who are not yet diagnosed and those with a diagnosis of dementia.

☎ 0121 521 3028

💻 blackcountryoffice@alzheimers.org.uk

Dementia Support Worker : Hard to Reach Groups

Specialise in supporting people who may not find accessing services easy such as people from black and ethnic minorities whose first language may not be English, the sensory impaired and those with a learning disability.

☎ 07788 385 446

💻 Sadat.hussain@accordha.org.uk

Dementia Advisers

Dementia Advisers are people with experience in dementia care who can offer information, usually over the phone on aspects of dementia care. They can be a good source of information and can refer you on if necessary for specialist help.

☎ 01922 707 898

☎ 01922 707 899

💻 advisers@ageukwalsall.org.uk



Here are some top tips to help you, help yourself.

Positive mental attitude

Try to stay positive. By staying positive, you will find having dementia much easier to adjust to. Try to concentrate on what you can do, rather than what you cannot do. You can still enjoy life but you have to make adjustments to get the most out of it.

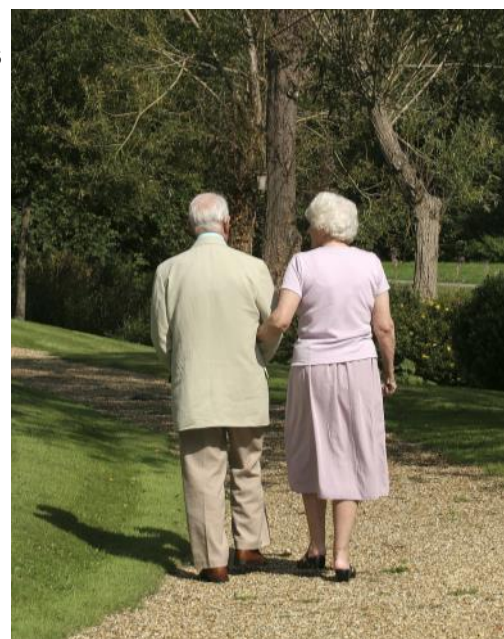
Maintain a good diet

It is very important that you eat well and drink plenty of fluids. If you do not eat well or become dehydrated from not drinking enough, you may become unwell and as a result, become confused.

Whilst many people enjoy an alcoholic drink, try to keep this to a minimum and seek advice if your medications warn against drinking alcohol.

Exercise

The benefits of exercise are just the same for people who have been diagnosed with dementia as for those people who have not. The important thing to consider is that it might be wise to have someone with you if you exercise outside of the home, or carry your address with you in case you should become lost.



Manage long term conditions

If you suffer from long term medical conditions such as diabetes, high blood pressure or high cholesterol, it is important that you continue to manage these conditions in order to stay well and to try and prevent your health from deteriorating. You may need to speak to your GP for advice or ask for a referral to someone else who may be able to help.

This could be in practical ways such as organising your medication into as fewer doses as possible or getting someone to remind you when to take tablets or help with your diet.

Socialise

People diagnosed with dementia often feel embarrassed to tell people about their diagnosis and withdraw from their usual social activities. However, most people close to you will already realise that you have had problems with your memory. By discussing your difficulties with them, it will much easier for both of you to find ways to cope with your difficulties together.

Continuing to take part in your usual activities where possible, will not only give you some purpose but it will enable you to enjoy yourself. Shutting yourself away will increase the chances of becoming depressed and socially isolated.

Humour

There will be times when things happen, or you do things which you might find embarrassing, irritating or frustrating. If you are able to find humour in these situations, it will make life much less stressful for both you and anyone whom you are close to. It also makes it easier to talk about things.

Keep to a routine

Keeping to a routine is one of the best memory prompts. By establishing usual patterns of behaviour, this in itself will become a prompt as well as make you feel more secure and less anxious.

One very useful thing to do is to always put important information, documents, keys or valuables in the same place so it is easy for you to find what you are looking for.



Make notes

Write down things you want to do and things you want to ask of people. Keep the notes in the same place, usually near to where you sit most often in your home. Refer to the notes regularly and ask other people to add to your notes. They might write down reminders for you. This should include important telephone numbers and contact details.

There are various useful prompts to help you to become orientated to time and date. Calendars, diaries, notice boards and clocks with date displays are very useful as prompts.

Because short term memory difficulties are a big problem in dementia, keeping track of what time and day it is can be very difficult to do. As a result, people can become disorientated. By having a calendar or diary close at hand, you can tick off the days to help keep you orientated. Asking someone to check this with you can be a good idea in case you tick off two days in one day. You can also record appointments, which otherwise would be difficult to remember.

Newspapers can also be useful in reminding you of dates and keeping up with what is going on in the world and clocks with date displays are a useful as a backup to your calendar or diary.

Notice boards can be a good visual clue and hold appointment cards, letters you want to show someone, a list of your medications and other useful pieces of information such as telephone numbers, etc.

Labels and notices

Some people like to use labels to help themselves find things around their home. For example, labels on cupboard doors to remind you where you keep tea and coffee or beside switches to remind you not to turn things off such as the fridge. Some people respond well to notices on doors suggesting that they do not go out by themselves as their dementia progresses.



Mental stimulation

Mental activity is helpful in passing the time, enjoying yourself, getting satisfaction from achieving something and may slow down the deterioration in your mental abilities. 'Brain training' activities such as puzzles, crosswords and quizzes are all useful things to do. Doing them with other people is even better and some people have found hand held games consoles and portable computers fun to use.

Simplify things

As time goes on, people with dementia will find every day activities more difficult. With this in mind, start to simplify things where possible. For example, if tying shoe laces are becoming a problem, buy slip-on shoes. If fastening buttons are a problem, try larger buttons, or avoid

buying clothing with small buttons. This could also apply to where you keep things in your home or with preparing food and cooking.

Multi-sensory stimulation

Try to vary the activities you do and make use of all of your senses. For example, listening to music, walking in gardens where you can smell flowers and herbs and enjoy creative activities where you can make things.

Information sharing

The 'Message in a Bottle Scheme' was introduced to enable emergency services to find information about people quickly. Information such as medical history, medication, allergies, next of kin, etc. is kept in a specially labelled plastic bottle in the fridge. A sticker is then placed on the front of the fridge and also on the back of the front door, reminding emergency staff that there is a bottle with information contained in it, within the fridge. The Lions International club give these out free of charge.

The 'Carers ID Key Fob Scheme' is literally a key fob which informs emergency services that if something happens to a carer, there is someone at home who may need assistance. It contains contact information and the names of other people who might be able to help.

The 'ICE - In Case of Emergency Scheme' involves people adding an entry called, 'ICE' in their mobile phone phonebook giving a next of kin number for emergency services to find, should something happen to the carrier of the phone.

Assistive technology

There are numerous devices available to help you stay independent. This could be in the form of electronic reminders to take tablets, warnings not to go outside, alerts to your family or devices to switch off your gas supply if you leave your cooker on without lighting it. There is even a satellite tracking device you can wear in a pendant in case you become lost so your family can find you!



The Gadget Gateway is a dedicated online resource that gives information on the assistive technology and telecare products available. For further information visit the Gadget Gateway website which will enable you to gain further support.

☎ 01922 650 790

💻 [The Gadget Gateway](#)


📍 Independent Living Centre, 9 Wisemore, Walsall. WS2 8EZ

For further details please contact the Independent Living Centre please look at the

 [Independent Living Centre Leaflet](#)

You can also buy many useful daily living equipment to support those with dementia to continue to help them maintain a degree of independence. Mindful Gifts is a social enterprise who might be able to help.

For further information please contact Vicki Phipps.

 07828 935 451 or 01922 495 994

 <http://www.mindfulgifts.co.uk>  mindful.gifts@yahoo.com

Life story

Many people find it very useful to write out their life story and include photographs in this. This can be a very enjoyable experience, be useful for reminiscence and something to refer back to if long term memories become clouded.

Apps (Adapted from Telford & Wrekin council guidance.)

What is an App?

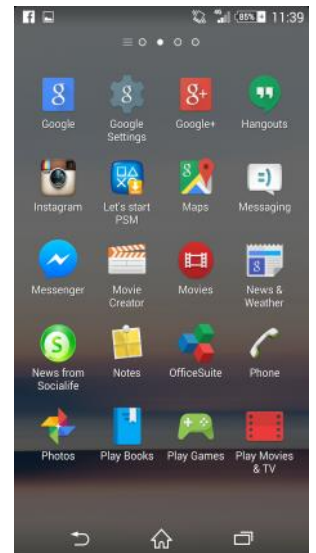
App is an abbreviation for application. An App is a piece of software that can run through the Internet, on your Computer, on your Smartphone, Tablet (a hand held computer) or other electronic device. Apps will have a specific task or function, like monitoring your health, managing your care, a utility such as a compass or calculator or just a game or puzzle. There are hundreds and thousands of Apps available so there really is something for everybody.

What can Apps help me to do?

Apps can help you do a number of things like help maintain or improve your memory, or advice and guidance on how to reduce slips and falls. Narrowing your focus to 'what area of your life you might need help with' will help you to find the right App.

Where do I get Apps from?

You access Apps through your smartphone, tablet or computer but you will need to be connected to the Internet to be able to do this. This could be through an Internet connection you may have in your home called 'broadband' (you usually have to pay for this) or through your mobile phone network usually called 3G or 4G. To download Apps there are a number of commonly used sites; which one you use will depend on the type of electronic device you have. Most Smartphones come with a preloaded App Store. The most common stores are Apple App Store, Google Play Store, Windows Phone Store and the Blackberry App World Store.



What do Apps cost?

Many Apps are free or there is a small cost to purchase them. There are special Apps that:

- May require you to purchase an additional gadget to help monitor your diabetes, blood pressure weight.
- Some Apps you get for free may only be reduced versions of a more expensive App.
- Some Apps, due to the level of functionality, are just expensive. You will have to make a decision if the cost of an App is worth it.

It is always worthwhile spending some time reading reviews of an App before you download it. That way you will learn from the experience of others which may help you decide:

If you want the App, if it is good value for money or whether you need it or not.

What does download mean?

Download means taking a copy of the App from the App Store and putting onto your computer, smartphone or tablet.

Is it difficult to download Apps and set them up?

Your device should come set up and ready to download Apps from the appropriate App Store.

You may need to enter your password or payment details. If it is your first time it's best to download a couple of free Apps first to get used to it, as you can always delete them later. Then when you first pay for an App you will be more confident.

Social Media

Social Media is a collection of online communication tools. Using these tools you can:

- Write something and share it with only your friends and family all at the same time
- Speak to friends and family from all over the world
- Link up with people who have similar interests or hobbies

You may have heard about two of the most popular social media sites when watching the TV, particularly the News. These two sites are called Facebook and Twitter. These are the symbols that you may have seen.



Fire safety

West Midlands Fire Service (WMFS) is committed to making the West Midlands safer and part of their promise to the community is to offer free Fire Safety Advice. The service is a tailored approach which is flexible enough to deliver to the needs of the most vulnerable individuals in the community, whilst maintaining an emphasis on Fire Safety. Their aims are:

- Identify and engage with vulnerable members of our community
- Target our services in the community to reduce the risks and improve safety, health and wellbeing;
- Engage with community groups, to make our communities safer;
- Empower our communities to make decisions about their safety.



They may be able to offer a FREE Home Safety Check or send you information on Fire Safety in the Home by calling our Freephone telephone number .

Visits will be made on an appointment only basis and will be arranged at a convenient time for you. The Home Safety Check will take about half an hour of your time and WMFS personnel will check your home to ensure there are no immediate fire hazards, give you fire safety advice in order to keep you safe from fire and also fit free smoke alarm(s) if required.

WMFS personnel will usually be wearing uniforms and will be carrying Photographic Identification Cards. Before allowing WMFS personnel into your home, always ask to see the Identification Card and if you require confirmation, telephone the Freephone helpline.



WEST MIDLANDS FIRE SERVICE

Home Safety Checks are free – your safety is their concern. For further information please call the Freephone helpline.

☎ 0800 389 5525 (please quote 2348)

All photographs on this page are the copyright of West Midlands Fire Service 2015

Section 4: Practical help

Whilst it is important to try and maintain your own independence, having a diagnosis of dementia means that at some point, you will require practical help from other people. This can be in many forms. Whilst it is always better to try to do what you can for yourself, having people to help do this with you, may make life not only easier but less stressful also.

Don't be embarrassed to ask for help. Ultimately practical help will enable you to cope better at home. Below are some examples of practical help:

Apply for Attendance Allowance

This is what the government website says about Attendance Allowance:

Attendance Allowance is a tax-free benefit for people aged 65 or over who need someone to help look after them because they are physically or mentally disabled. You may get Attendance Allowance if:

- You have a physical disability (including sensory disability, such as blindness), a mental disability (including learning difficulties), or both
- Your disability is severe enough for you to need help caring for yourself or someone to supervise you, for your own or someone else's safety
- You are aged 65 or over when you claim

The helpline for attendance allowance is ☎ 0345 605 6055 (Monday to Friday 8.00 am – 6.00 pm) 🖨 [Claim form](#)

Normally, you must have had these care or supervision needs for at least six months. However, if you are terminally ill, there are special rules for claiming the benefit. Attendance Allowance is not usually affected by any savings or income you may have. To get Attendance Allowance, your disability must be severe enough for you to need any of the following:

- Help with things such as washing (and getting in or out of the bath or shower), dressing, eating, getting to and using the toilet, or communicating your needs
- Supervision to avoid putting yourself or others in substantial danger, for example, needing someone to keep an eye on your medical condition or diet, or because you cannot control the way you behave

The image shows a screenshot of the 'Attendance Allowance for people aged 65 or over' claim form. The form is titled 'Attendance Allowance for people aged 65 or over' and includes the Department for Work & Pensions logo. It instructs the user to fill in the form and send it back as soon as possible. A note states: 'Please fill in this claim form and send it back to us as soon as you can. We can only consider paying benefit from the day we receive it.' Below this, there is a link to read page 2 of the notes. The form is divided into sections: 'About you' and 'What is your nationality?'. The 'About you' section includes fields for: 1. Surname or family name, 2. All other names in full, 3. National Insurance number, 4. Date of birth (day/month/year), 5. Sex (Male/Female), 6. The full address where you live, 7. Daytime phone number (including dialing code), 8. Mobile phone number (if different), 9. Textphone number (if you have speech or hearing difficulties and want us to contact you by textphone, please tick this box), and 10. What is your nationality? (Please see question 7 in the notes booklet). The form is dated AA1A July 2014.

- Someone with you when you are on dialysis

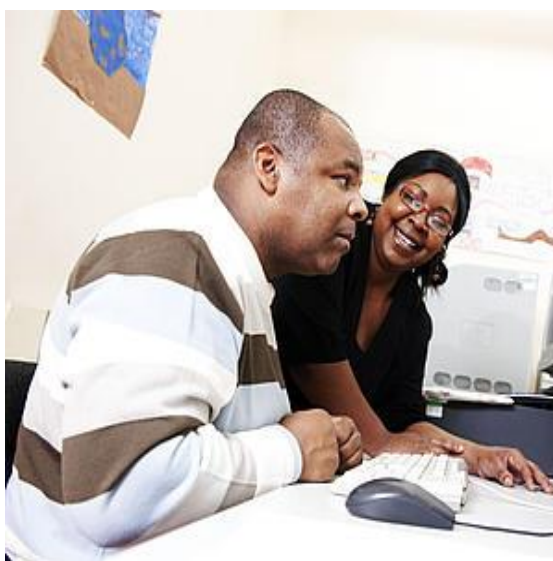
It's paid at two different rates and how much you get depends on the level of care that you need because of your disability:

- The lower rate, if you need help with personal care frequently or supervision continually throughout the day only, help with personal care or someone to watch over you during the night only, or someone with you when you are on dialysis.
- The higher rate, if you meet both a day and a night condition for the middle rate, or if you are terminally ill and claiming under special rules.

You can get Attendance Allowance even if no one is actually giving you the care you need - even if you live alone.

If you are under age 65, you may be able to get Disability Living Allowance.

Welfare Rights



The Welfare Rights Service in Walsall offers a range of services to residents to help gain full entitlement to welfare benefits but also to help concentrate on quality of life improvements.

- Full welfare benefit checks are completed.
- Income Maximisation through the benefit system

☎ 01922 652 250

📍 Walsall Council, 1st Floor Civic Centre, Darwall Street, Walsall. WS1 1XU

💻 welfarerights@walsall.gov.uk

Informal help

This can be from friends, family and neighbours. Examples are going shopping with people so that they can prompt you to buy the foods you need, preparing food, reminding you to take tablets or helping you put clothes out in the order that it is easiest to put them on.

Voluntary organisations

There are several local and national organisations that may be able to offer practical help and advice. You can find them by searching the Internet, or by visiting your local library, council or Citizen's Advice centre.

Council tax

As your dementia progresses, you may be entitled to a council tax rebate. When your GP feels you are able to qualify they can fill out a medical report form, which you can give to the council tax office. To qualify for this rebate you must be said to have, 'severe mental impairment' and this would entitle you to become invisible for council tax purposes. This means that if you live alone you will not pay council tax and if you have a partner, they will be counted as single and therefore receive a 25% discount even though you are still living there. Please note that this is not usually applicable to people with mild dementia. Ask your GP about this or the Memory Assessment Service for advice.

Social Care – What we do

Safeguarding of vulnerable adults and older people

Arrange adult social care support for:

- Adults with mental health needs
- Older people with physical or mental health needs including dementia (including self funders)
- Adults with physical disability or sensory impairment
- Adults with a learning disability
- Adults with autism
- Young people with physical disability, sensory impairment, learning difficulty or autism who are in transition to adult social care services
- Carers of adults and older people

For all adult social care user groups we provide:

- Information, advice and signposting on sources of support
- Individual, family and community capacity building to achieve and retain independence
- Facilitation of access to universal services
- Preventative services that lead to regaining and retention of independence
- Community alarms and telecare
- Reablement services that lead to regaining and retention of independence
- Support for carers to enable them to undertake and continue their caring role
- Out of hours emergency on call service
- Assessment of need of eligible adults and older people
- Allocation of personal budgets
- Validation and review of support plans
- Market shaping and development and the commissioning of services



Please use the following details for all social care queries:

☎ 0300 555 2922 or 📠 01922 652 922

Please note the 01922 number may not be available in emergencies.

Fax 01922 478 195 Text phone 01922 654 000 SMS text 07913 629 085

📍 Civic Centre Darwall Street Walsall WS1 1TP

📧 Initialintake@walsall.gov.uk

Ask for a social worker needs assessment if you feel you may need practical help at home. You can be assessed in your home and if you have a carer, they can request a carer assessment in their own right. Whilst you may not have someone you would call a 'carer' if you have been newly diagnosed, there may come a time when you would want the help of someone close to you such as a family member, friend or neighbour. If this becomes necessary, they may find it helpful to develop a carer support plan. This details the difficulties that you both face because of dementia and what is planned to help to try and address those difficulties. Look under council in the phonebook. Please note that you be asked about your finances and you will need to fulfil their eligibility criteria.



Walsall Community Living Directory

It is recognised that support is provided by family and friends as well as working with community organisations and activities. Walsall Council works with partner agencies to ensure that relevant information and support can be readily available for those in need. For information on what other services are available.

📧 [See Web Directory](#)



Self directed support

Self directed support is about people being in control of the support they need to live their life as they choose.

Some people manage their support on their own. Others need help - from family or friends or people who are paid to help.

In the traditional system, professionals like social workers made all the decisions about the support people could have and who would provide it. The person needing support often felt they had no control.

There are a number of different types of self directed support. These include:

- Direct payments
- Personal budgets
- Individual budgets

What is a direct payment?

A direct payment (DP) is a sum of money in lieu of Social Care Services. The money is given to individuals by Social Services to buy the support they have been assessed as needing.

Direct payments are an important way of ensuring that more people can live independently in their own homes. As such they promote independence, choice and inclusion by enabling people to purchase assistance or services that the Council would otherwise provide in order to live in their own homes.

What is a personal budget?

A personal budget is the funding given to someone after they have been assessed and which should meet their needs. They can have the money as a direct payment or can choose to manage it in different ways. What is important is that these budgets give people a clear amount of money and the right to choose how this is managed and spent.

What is an individual budget?

An individual budget is an overall budget for a whole range of services - not just from social care - which you can choose to receive as cash or services or a mixture of both. Individual budgets combine money from the different agencies that currently help you. These might include:

- Local authority adult social care
- Integrated community equipment services

- Disabled Facilities Grants
- Access to Work
- Independent Living Fund.

What is a self assessment questionnaire?

A self assessment questionnaire (SAQ) is a way for the council to understand what support you may need and to estimate the risks to you if the help is not provided. The council then use this information to decide what money or budget you can have to help you meet your needs. It will help you think about different areas of your life and what level of care and support you need to achieve maximum independence.

The SAQ can be completed by you, or you may prefer to do it with help and advice from other people, such as friends or family, or someone from adult social care.

What is a resource allocation system?

A resource allocation system or RAS is the way the council work out what is a fair and reasonable amount of money for people to have in their personal budget. When your assessment has been completed, points will be attached to the answers and these will then be converted into money for your budget.

What is a support plan?

Once you have completed your self assessment questionnaire and financial assessment and know what money is available to you to spend, you will be asked to complete your support plan.

You can complete it on your own or with the help of friends, family or a social worker/care manager.



Your support plan is intended to identify the things that are important to you and what you would like to change to help you live the best quality of life that is possible.

It should look at your whole life and what's working and not working for you. It should identify the help and support that you feel you need and how you would like to receive that assistance.

There will be different ways of preparing your support plan. You can write things down, use pictures and diagrams and different ways of presenting the information like DVDs. It will look at things like:

- What is important to me?
- What do I want to change?
- How will I get the support I need?
- How will I use my personal budget?
- How will I manage and stay in control of my support?
- How will I make this happen?

A support plan does not have to be complicated; you can make it as detailed or simple as you want.



Occupational therapy assessment

You can ask for an occupational therapy assessment if you are having difficulties in your home with for example, getting into the bath. The occupational therapist will assess you and advise on any adaptations that would benefit you. This may include assistive technologies. Look under council in the phonebook.

Domiciliary Care

Domiciliary Care is provided by numerous private agencies or by the council if you fulfil their eligibility criteria. Private agencies will do a range of interventions to help you. This ranges from shopping, prompting to take tablets, preparing and cooking food, cleaning and personal care – helping you wash and dress.

The council home care interventions tend to be aimed more at personal care and for people whose dementia has advanced. You can use Attendance Allowance to help pay for this kind of service. Lists of home care agencies can be obtained from the Care Quality Commission.

Care Quality Commission (CQC): <http://www.cqc.org.uk/>

Day care and activities

These are centres where you can go for a day or more a week and take part in activities designed to benefit people with dementia. These are usually group activities such as orientation groups, creative groups or 'brain training' type groups. People usually enjoy the social side of these places and look forward to getting out of their home for a while. This can also give carers a break and give them opportunity for time for themselves.

Some of these services are run by voluntary organisations and some are privately owned. You will need to contact Social Care Services and a needs assessment will be carried out.

Stan Ball Centre – offers support / activities for further details to contact the centre.

☎ 01922 403 351

📍 Stan Ball Centre, Abbotts Street, Walsall. WS3 3BW

The Water Mill

The Water Mill provides Day Care for older people with dementia who live in the Borough of Walsall. The Day Centre takes up to 20 people a day, 7 days a week. The support and care is provided around each individual person's needs, helping to improve quality of life and to encourage independence.

☎ 03701 924 220

📍 The Water Mill Goscote Hospital Site, Goscote Lane, Walsall. WS3 1SJ



Ace Day Centre

Provides day care in Walsall, specialising in caring for those diagnosed with dementia.

☎ 01543 454 438

📍 New Rd, Brownhills, Walsall WS8 6AT

Walsall Link Line

Provides reminiscence therapy, a dementia café, activities and support for carers.

📍 St Catherine's with Chad's Church, Edison Road, Beechdale Walsall. WS2 7HT

☎ 01922 6400 916 / 07742 917 766

📧 mandykeay@yahoo.com

Photograph copyright of Housing & Care 21

Dementia Cafés

Dementia cafés are places for social interaction, support and information. They are for people with dementia and their carers. They give people the opportunity to share thoughts, concerns and ideas and have a good time. There are seven free community dementia cafés in Walsall and one dementia café in Walsall Manor hospital.

☎ 07793 699 141

🖨 [Dementia Cafes](#)

Aldridge Café

Old Rectory Gardens, The Green,
Aldridge, Walsall, WS9 8UP

Fourth Tuesday of each month

From 2.00pm to 4.00pm

Pelsall Café

Old Vicarage, Old vicarage Close,
Pelsall, WS3 4AZ

Third Thursday of each month

From 6.00pm to 8.00pm

Independent Living Centre (ILC)

9 Wisemore, Walsall, WS2 8EZ

First Friday of each month

From 2.00pm to 4.00pm

Brownhills Café

Brownhills Community Association,
Community Activity Centre,
Chester Road North,
Brownhills, WS8 7JW

Third Wednesday of each month

From 2.00pm to 4.00pm

Willenhall Café

Willenhall Chart, 19 Gomer Street,
Willenhall, West Midlands, WV13 2NS

Second Wednesday of each month

From 2.00pm to 4.00pm

Walsall Café

Apna Ghar, Ford Street, Walsall,
WS2 9BW

Third Friday of each month

From 6.00pm to 8.00pm

Bloxwich Café

Furlong House, Lanton Close,
off Kempthorne Gardens, Bloxwich,
WS3 2LJ

First Wednesday of each month

From 2.00pm to 4.00pm

For more information, email the
Dementia Café Co-ordinator on:

walsalldementiacafes@accordgroup.org.uk
or call 07793 699 141 or 0300 111 7000

Respite stays

Respite involves going into a residential home for a week or so to give your carer a break and give them the opportunity to re-charge their batteries. It also gives you the opportunity for social interaction and to take part in activities at the home. If you require assistance with personal care, the staff at the home will assist you. Look under council in the phonebook for this service, which is accessed via a social work needs assessment. You will be asked about your finances and you will need to fulfil their eligibility criteria.

Dementia and Oral Health

In the early stages people with dementia may struggle with, or forget about maintaining good oral hygiene. As the dementia becomes progressively worse, carers will need to assist. In the advanced stages, dental treatment may be difficult or virtually impossible, particularly in cases of profound confusion or aggression. There are two main types of dental disease – gum (periodontal) disease and tooth decay (dental caries). Both can cause discomfort or pain and can lead to the development of infection. Both pain and infection can worsen the confusion associated with dementia.

To try and ensure good oral health:

- Brush using a small headed toothbrush with medium textured bristles at least twice a day (especially at night) using a toothpaste that contains fluoride. Where possible try to spit out after brushing and do not rinse.
- As manual ability decreases, an electric toothbrush may help maintain independence. The person with dementia could also try using a toothbrush with an adapted handle to improve their grip
- Where possible try to keep sugary foods and drinks to mealtimes to reduce the risk of tooth decay. If supplements are required then seek professional support on this.
- Visit your dentist and hygienist regularly, as often as they recommend. They may prescribe products to help prevent tooth decay and a dry mouth.

The Alzheimer's Society has produced an excellent leaflet on Dental Care and Dementia. To find an NHS Dentist in Walsall:

 www.nhs.uk

 <http://www.alzheimers.org.uk>



Community Continence

If you are having difficulties with wetting yourself, sudden urges to go to the toilet or leaking/dribbling, inform your GP who will investigate the problem and if necessary they can refer you to a continence nurse. There are many potential causes of continence problems, so it is important to get it checked out. There is a nurse led service offering holistic assessment, advice and management of continence related issues for clients of all ages, male and female within the Borough of Walsall. The service is provided within primary care clinics, clients' own homes (if housebound), residential and nursing homes. There are several clinics available within Walsall, You are able to self refer and these can be sent to email below.

☎ 01922 605 940 / 605 947

💻 continence.service@walsall.nhs.uk

Memory Assessment Service (Memory Clinic) and Community Mental Health Teams

These include nurses, occupational therapists, social workers, psychiatrists, psychologists and support workers. You will probably already be familiar with staff from these services - particularly the Memory Assessment Service. However, as the dementia progresses, you may see staff from the community mental health team and they will support you in your home. They work with people with dementia all the time and have a vast experience in this area and can advise on strategies for dealing with difficult situations. They are also expert in caring for the carer.

Blue Badge Scheme

The Blue Badge Scheme is a national arrangement of parking concessions for people with severe walking difficulties who travel either as drivers or passengers. The scheme also applies to people who are registered blind or severely sight impaired, and people with very severe disabilities in both arms who regularly drive a vehicle but cannot operate or have considerable difficulty in operating all or some types of parking meter. It allows badge holders to park close to their destination, but the national concessions apply only to on-street parking. This scheme is governed by National Eligibility Criteria set out by the Department of Transport.



Information in relation to applying for Blue Badge, FAQs can be found here:

💻 [Blue Badge Scheme](#)

Section 5: Planning for the future

By planning for the future, you will be able to make decisions about your care in advance. This involves letting people know your wishes, enlisting the help and support of others and putting your affairs in order. This is a list of things to consider when you do this:

Speak to people you trust

This has been mentioned several times in this document but it is important to discuss your feelings and concerns with people you trust, such as your family and friends. They will be able to support you in making these important decisions or help you find professional assistance. If you choose to see people like solicitors for advice, it is still advisable to take someone you trust with you, as they will prompt you to discuss important issues for you and help you remember the outcome of the meeting.

Independent Advocacy

For older people living with dementia, independent advocacy can be an invaluable resource for many reasons. Independent advocacy provides a way of making sure an older person with dementia can express their wishes and views that they are able to speak up and have their voice heard and that people around them - whether professionals, friends or family - do not lose sight of the unique individual that sits behind a diagnosis of dementia.



All too often the voice and wishes of a person with dementia can be easily lost amongst the competing perspectives of the many people that may unexpectedly become involved in their life, suddenly everybody else may have an opinion on “what is best” for the person and although the best of intentions may be their motivation this does not take away the fact that the person with dementia slowly starts to lose all control, authority and choice over their own life and circumstances.

A trained and qualified independent advocate will have well developed communication skills and be able to work with a wide variety of communication skills and tools which may help a person with dementia to express themselves more fully and also better understand information being given to them in a personalised format.

The involvement of an independent advocate can also assist other people working with a person who has dementia so that they can capture the individual’s beliefs and wishes and ensure these are always taken fully into consideration in any decisions being made about them.

If you would like receive more information to contact Advocacy Matters:

☎ 0121 321 2377

💻 <http://www.advocacymatters.co.uk/>

Consider making a will

Everyone should make a will. A will makes sure that when someone dies, their money and possessions go to the people they have chosen. It is important to make a will as early as possible after diagnosis. With a diagnosis of dementia, you can only make a will when you are said to have, 'testamentary capacity'.

In other words, the mental capacity to make or change wills. Where there is doubt, a solicitor may require a medical opinion on testamentary capacity. Mental capacity is assumed and where there is doubt, the assessing doctor should address the question: "Is it more probable than not that this person lacks or has testamentary capacity?" This assessment would be specifically for this decision. Capacity for other decisions would have to be assessed separately.



Mental capacity

The Social Care Institute for Excellence's publication on mental capacity explains about the Mental Capacity Act (2005) and how this affects people diagnosed with dementia.

'The Mental Capacity Act (MCA) is underpinned by five key principles:

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. This means that you cannot assume that someone cannot make a decision for themselves just because they have a particular medical condition or disability.

Individuals being supported to make their own decisions – a person must be given all practicable help before anyone treats them as not being able to make their own decisions. This means you should make every effort to encourage and support people to make the decision for themselves. If lack of capacity is established, it is still important that you involve the person as far as possible in making decisions.

Unwise decisions – people have the right to make decisions that others might regard as unwise or eccentric. You cannot treat someone as lacking capacity for this reason. Everyone has their own values, beliefs and preferences which may not be the same as those of other people.

Photograph copyright of Accord Group

Best interests – If a person has been assessed as lacking capacity then any action taken, or any decision made for or on behalf of that person, must be made in his or her best interests. The person who has to make the decision is known as the ‘decision-maker’ and normally will be the carer responsible for the day-to-day care, or a professional such as a doctor, nurse or social worker where decisions about treatment, care arrangements or accommodation need to be made.

Less restrictive option – someone making a decision or acting on behalf of a person who lacks capacity must consider whether it is possible to decide or act in a way that would interfere less with the person’s rights and freedoms of action, or whether there is a need to decide or act at all. Any intervention should be weighed up in the particular circumstances of the case.

When should capacity be assessed? - You might need to assess capacity where a person is unable to make a particular decision at a particular time because their mind or brain is affected by illness or disability. Lack of capacity may not be a permanent condition. Assessments of capacity should be time and decision specific. You cannot decide that someone lacks capacity based upon age, appearance, condition or behaviour alone.

Two-stage functional test of capacity - In order to decide whether an individual has the capacity to make a particular decision you must answer two questions:

Stage 1: Is there an impairment of or disturbance in the functioning of a person’s mind or brain? If so,

Stage 2: Is the impairment or disturbance sufficient that the person lacks the capacity to make a particular decision?

The MCA says that a person is unable to make their own decision if they cannot do one or more of the following four things:

- Understand information given to them
- Retain that information long enough to be able to make the decision
- Weigh up the information available to make the decision
- Communicate their decision – this could be by talking, using sign language or even simple muscle movements such as blinking an eye or squeezing a hand.



Every effort should be made to find ways of communicating with someone before deciding that they lack capacity to make a decision based solely on their inability to communicate. Also, you will need to involve family, friends, carers or other professionals.

The assessment must be made on the balance of probabilities – is it more likely than not that the person lacks capacity? You should be able to show in your records why you have come to your conclusion that capacity is lacking for the particular decision.

For further reading on the Mental Capacity Act (2005)

🖨 <http://www.scie.org.uk/adults/mentalcapacity.asp>

Work

If you are still in work, be aware that in time, dementia will make you less able to do your job. In fact you will eventually have to give up your job. However, there may be options you could discuss with your employer such as, shorter hours, a simpler job or early retirement. Having someone with you for these discussions is advisable. Now would be a good time to look into what pension you would be entitled to and any other benefits you could apply for when you give up work.

Driving

Dementia will affect your ability to drive and at some point you will have to give up driving. However, some people are able to still drive for a period of time after diagnosis; particularly if diagnosed early. The Driving Assessment Centre has lots of information on driving with medical conditions and on the driving skills assessment process.

Download and complete this medical questionnaire:

🖨 http://www.direct.gov.uk/prod_consum_dg/groups/dg_digitalassets/@dg/@en/@motor/documents/digitalasset/dg_171291.pdf

and send it to 📧

Drivers Medical Group
DVLA
Swansea
SA99 1DF

📧 eftd@dvla.gsi.gov.uk

The DVLA may ask your GP and your hospital specialist about your fitness to drive. Your GP and hospital specialist have to give an honest opinion, based on the guidance issued to them and have a duty to report drivers who may be unfit to drive. Whilst GPs and hospital specialists never like recommending people give up their driving licence, they have a duty of care to all road users and pedestrians and must consider this when giving an opinion on your ability to drive. This is not a reflection on you as a driver but the way in which dementia affects your ability to drive.



The guidance below is for car and motorcycle users only. Those drivers with VOC – LGV/PCV will have their license revoked immediately.

Guidance from the DVLA for Professionals:

The GMC has issued clear guidelines applicable to such circumstances, which state the following:

1. The driver is legally responsible for informing DVLA about such a condition or treatment. However, if a patient has such a condition, you should explain to the patient:
 - a) That the condition may affect their ability to drive (if the patient is incapable of understanding this advice for example because of dementia, you should inform DVLA immediately) and,
 - b) That they have a legal duty to inform DVLA about the condition.
2. If a patient refuses to accept the diagnosis, or the effect of the condition of their ability to drive, you can suggest that they seek a second opinion, and help arrange for them to do so. You should advise the patient not to drive in the meantime.
3. If a patient continues to drive when they may not be fit to do so, you should make every reasonable effort to persuade them to stop. As long as the patient agrees, you may discuss your concerns with their relatives, friends or carers.
4. If you do not manage to persuade the patient to stop driving, or you discover that they are continuing to drive against your advice, you should contact the DVLA immediately and disclose any relevant medical information, in confidence, to the medical adviser.
5. Before contacting DVLA, you should try to inform the patient of your decision to disclose personal information. You should also inform the patient in writing once you have done so.



Lasting powers of attorney

The Office of the Public Guardian offers useful advice on lasting powers of attorney (LPAs) written below:

An LPA is a legal document that you (the Donor) make using a special form. It allows you to choose someone **now** (the Attorney) that you trust to make decisions on your behalf about things such as your property and financial affairs or health welfare at a time in the future when you no longer wish to make those decisions or you may lack the mental capacity to make those decisions yourself. An LPA **can only be used** after it is registered with the OPG.



The types of LPA

There are two different types of LPA:

Health and Welfare Lasting Power of Attorney

A health and welfare Lasting Power of Attorney (LPA) allows you to plan ahead by choosing one or more people to make decisions on your behalf regarding your personal healthcare and welfare.

These health and welfare decisions can only be taken by somebody else when you lack the capacity to make them for yourself; for example if you are unconscious or because of the onset of a condition such as dementia.

The Attorney(s) you appoint to make personal welfare decisions will only be able to use this power once the LPA has been registered and provided that you cannot make the required decision for yourself. You can decide to give your Attorney the power to make decisions about any or all of your health and welfare matters. This could involve some significant decisions, such as:

- Giving or refusing consent to particular types of health care, including medical treatment decisions; or
- Whether you continue to live in your own home, perhaps with help and support from social services, or whether residential care would be more appropriate for you.

If you want your Attorney(s) to have the power to make decisions about 'life-sustaining treatment', **you have to** expressly give your chosen Attorney(s) the power to make such decisions by choosing either option A or option B in section 5 of the health and welfare LPA form.

You can also give your Attorney(s) the power to make decisions about day-to-day aspects of your personal welfare, such as your diet, your dress, or your daily routine. It is up to you which of these decisions you want to allow your Attorney to make.

This type of LPA does not allow the person(s) you have chosen (your Attorney) to make decisions about your property and financial affairs. If you would like someone to be able to make property and financial affairs decisions on your behalf you will need to make a property and financial affairs Lasting Power of Attorney.

The property and financial affairs Lasting Power of Attorney

A property and financial affairs Lasting Power of Attorney (LPA) allows you to plan ahead by choosing one or more people to make decisions on your behalf regarding your property and financial affairs.

You can appoint a property and financial affairs Attorney to manage your finances and property whilst you still have capacity as well as when you lack capacity.

For example, it may be easier for you to give someone the power to carry out tasks such as paying your bills or collecting your benefits or other income. This might be easier for lots of reasons: you might find it difficult to get about or to talk on the telephone, or you might be out of the country for long periods of time. You can decide to give decisions about any or all of your property and financial affairs matters. This could include paying your bills, collecting your benefits or selling your house. This might be easier for lots of reasons: you might find it difficult to get about or to talk on the telephone, or you might be out of the country for long periods of time. You can decide to give your Attorney(s) the power to make decisions about any or all of your property and financial affairs matters. This could include paying your bills, collecting your benefits or selling your house.

This type of LPA does not allow the person(s) you have chosen (your Attorney) to make decisions about your personal welfare. If you want someone to be able to make health and welfare decisions on your behalf you will need to make a Health and Welfare Lasting Power of Attorney.



Who can make an LPA?

Anyone aged 18 or over, with the capacity to do so, can make an LPA appointing one or more Attorneys to make decisions on their behalf. You cannot make an LPA jointly with another person; each person must make his or her own LPA.

People involved in making an LPA

The following are the different people involved in making an LPA:

The Attorney(s)

An Attorney is the person(s) you choose and appoint, using an LPA form, to make decisions on your behalf about either your health and welfare or property and financial affairs or both. It is an important role and one that the person chosen has to agree to take on.

Donor

A Donor is someone who makes an LPA appointing an Attorney(s) to make decisions about his/her health and welfare, property and financial affairs or both.

Named person(s)

A named person is someone chosen by the Donor to be notified when an application is made to register their LPA. They have the right to object to the registration of the LPA if they have concerns about the registration. The named person(s) are specified in the LPA form. Selecting people to notify of an application to register is one of the key safeguards to protect you if you make an LPA.

Certificate provider

A certificate provider is a person the Donor must select to complete a Part B Certificate in the LPA form. The certificate provider must confirm that the Donor understands the LPA and that the Donor is not under any pressure to make it. The certificate provider is another important safeguard.

Witness

A witness is someone who signs the LPA form to confirm that they witnessed:

- * the Donor (the person making the LPA) signing and dating the LPA form; or
- * the Attorney(s) (the person appointed by the Donor) signing and dating the LPA form.

It is an important role and acts as a further safeguard.

More information can be obtained from their website including application packs:

 <http://www.publicguardian.gov.uk/index.htm>

Medical arrangements

This includes living wills, advanced decisions to refuse treatment and preferred priorities of care. By thinking about these things as soon as possible after first diagnosis, you will be able to say what healthcare you would like to have or not to have in the future.

People often have strong views about this, so it is important to write these views down and discuss your wishes with your friends, family and your GP.



The government produces guidance on living wills detailed below:

You can use an advance decision (also called advance directive) to indicate your wish to refuse all or some forms of medical treatment if you lose mental capacity in the future. You can't use it to request treatment.

A valid advance decision has the same effect as a refusal of treatment by a person with capacity: the treatment cannot lawfully be given - if it were the doctor might face civil liability or criminal prosecution.

Limitations on advanced decisions

You can't use an advance decision to:

- Ask for your life to be ended
- Force doctors to act against their professional judgment
- Nominate someone else to decide about treatment on your behalf

As with advance statements, bear in mind that new drugs or treatments may be introduced in the future so you may wish to allow for new treatments even if refusing a current one.

Does an advance decision have to be in writing?

An advance decision doesn't all have to be in writing. However, although witnessed verbal instructions may be respected, it's best to make them known to a senior member of a medical team. A written decision helps to avoid any doubt about what you wish to refuse. In any case, since April 2007 some aspects of advance decisions have to be in writing.

You should sign, date and have witnessed a written advance decision in the same way as for an advance statement. A written advance decision could form part of a general advance statement, but it is clearest if it sits under a distinct heading, ideally 'Advance decision' or 'Advance directive, refusing treatment'.

Regulations of advanced decisions from April 2007

The Mental Capacity Act 2005 came into force in April 2007 and forms the legal basis for advance decisions.

Valid advance decisions

To be valid an advance decision needs to:

- Be made by a person who is 18 or over and has the capacity to make it
- Specify the treatment to be refused (it can do this in lay terms)
- Specify the circumstances in which this refusal would apply
- Not have been made under the influence or harassment of anyone else
- Not have been modified verbally or in writing since it was made



Refusal of life-sustaining treatment

Advance decisions refusing life-sustaining treatment must:

be in writing (it can be written by a family member, recorded in medical notes by a doctor or on an electronic record)

be signed and witnessed (it can be signed by someone else at the person's direction - the witness is to confirm the signature not the content of the advance directive)

include an express statement that the decision stands 'even if life is at risk'

When might an advance decision not be followed?

A doctor might not act on an advance decision if:

- The person has done anything clearly inconsistent with the advance decision which affects its validity (for example, a change in religious faith).
- The current circumstances would not have been anticipated by the person and would have affected their decision (for example, a recent development in treatment that radically changes the outlook for their particular condition).
- It is not clear about what should happen.
- The person has been treated under the Mental Health Act.

A doctor can also treat if there is doubt or a dispute about the validity of an advance decision and the case has been referred to the court.

Preferred priorities of care

The National End of Life Programme is an NHS organisation charged with improving the end of life for people. Below you will find information from them on this programme and a document to download.

This patient held document was designed to facilitate patient choice in relation to end of life issues. Through good communication and by documenting patient and carers' choices, they become empowered through the sharing of this information with all professionals involved in their care. The PPC document provides the opportunity to discuss difficult issues that may not otherwise be addressed to the detriment of patient care. The explicit recording of patients' / carers' wishes can form the basis of care planning in multi-disciplinary teams and other services, minimising inappropriate admissions and interventions.



The PPC also records services available, services being accessed and reasons for changes in the care trajectory. PPC is a process, which facilitates service review, further empowering

professionals to negotiate service requirements on the behalf of patients, becoming an integral part of service commissioning and design.

Living arrangements

When first suspecting a diagnosis of dementia, people often put off going to see their GP because they are concerned that once a diagnosis is established, they will be taken into care. In fact quite the opposite is true. Every effort is made to enable people to stay living in their own home with services being offered to facilitate this independence. However, there may come a time when you feel unable to continue living alone. Below is a summary of some of the options available to people.

Live in carer

Live in carers can help people to stay living in their own home. Essentially, the carer lives with you and helps you with your daily living activities such as washing, dressing, preparing and cooking food and maintaining your safety. The drawback is that this is a very costly way of caring for someone and is usually more expensive than residential care.



Living with family

Whilst this may seem an attractive proposition, it has many pitfalls. For example, it puts a tremendous strain on relationships between the family you are moving in with as well as the relationship between you and the family who would be your carers. This is a very different relationship to the one you would have always enjoyed with them and so both you and they should think very carefully before making this

move. It could also affect finances if some of your money is used to buy a larger house suitable for all of you and then you later have to move into residential care because this move has not worked out.

Assisted Living

This is a residential option for those who want or need support with some of the activities of daily living. This offers the safety and security of 24 hour support and access to care day or night. There are different facilities available across Walsall and you will need to have an assessment carried out to enable your needs to be met that can accommodate you whilst giving you the freedom to do what you can for yourself.

Emergency Carers Service

There is an emergency response service available to enable carers to have support should an emergency occur. This is defined as an unforeseen or unplanned event where there is an element of distress or disruption and possible safeguarding issues for the cared for. Sevacare

is commissioned by Walsall Council to provide services which is available 24/7 and provide support for up to 72 hours. This will reduce anxiety for both carers and the cared for. You can register in advance for this service or self-refer at the time you need the support.

☎ 0800 148 8920

The Care Act

The Care Act 2014 strengthens the rights and recognition of carers in the social care system and comes into effect in April 2015. If you are looking after someone, find out about your rights as a carer and where you go for financial or practical help.

📖 Carers Right Guide

Residential care

Residential homes are places where people usually have their own room and often en suite facilities also. There are shared living rooms, dining rooms and bathrooms. The benefit is that other people do the washing up, cleaning and cooking! There are people around to socialise with and someone to keep an eye on you in case you should become unwell and to keep you safe. Some of these homes specialise in the care of people with dementia.

Lists of residential or care homes as they are sometimes called can be obtained from the Care Quality Commission who has a duty to inspect these homes.

📖 <http://www.cqc.org.uk/>



Access to care homes depends on need and finances. People who need assistance with funding for care homes, must do so with the help of a social worker and will have to fulfil the criteria. People who are funding the care home themselves, can make arrangements directly with the home.

Nursing care

Nursing care is very similar to residential care but it is for people who have nursing needs. This is because their dementia has progressed to a level which is beyond what residential care can manage or that there are medical conditions which require regular nursing interventions which can only be delivered in a nursing home environment. As the name implies, nursing homes have qualified nurses on duty at all times. Some of these homes specialise in the care of people with dementia.

Lists of nursing homes can be obtained from the Care Quality Commission who has a duty to inspect these homes.

Some of the costs of funding nursing care could be made by the NHS, following a nursing assessment.

 <http://www.cqc.org.uk/>

NHS Continuing health care

NHS Choices publish the following information:

NHS continuing healthcare means a package of care that is arranged and funded by the NHS and is free of charge to the person receiving the care. This is sometimes called fully funded NHS care.

Clinical commissioning groups (who manage local health services) are required to carry out an assessment for NHS continuing healthcare where health services might be needed. A checklist is commonly used to decide whether someone needs a full assessment. Some people who need an urgent decision, such as those who are terminally ill, should be fast-tracked to receive NHS continuing healthcare immediately.

Where is NHS continuing healthcare offered?

NHS continuing healthcare can be provided by the NHS in any setting, including a care home, hospice, hospital or the home of the person you look after. If NHS continuing healthcare is provided in a care home, it will cover the care home fees, including the cost of accommodation, personal care and healthcare costs. If NHS continuing care is provided in the home of the person you look after, it will cover personal care and healthcare costs.



Responsibilities of social services

If NHS continuing healthcare is provided at the home of the person you look after, local social services may still have responsibilities to provide some services for you and the person you're looking after. It is possible to receive 'mixed' packages of care, where some services come from the NHS and some from social services.

Where local social services provide the care services, it will usually do a financial assessment to decide whether the person you look after must make any financial contribution.

Who qualifies?

The person being assessed should have a comprehensive assessment by any of a range of the healthcare professionals involved in their care. There should be clearly identified professionals who will co-ordinate the process.

The team will consider each of the healthcare needs of the person you're looking after. These are:

- Behaviour,
- Cognition (understanding),
- Communication,
- Psychological/emotional needs,
- Mobility,
- Nutrition (food and drink),
- Continence,
- Skin (including wounds and ulcers),
- Breathing,
- Symptom control through drug therapies and medication, and
- Altered states of consciousness.



Those carrying out the assessment should look at what help is needed, how complex these needs are, how intense and unpredictable these needs can be, as well as any risks that would exist if adequate care was not provided. For each of these issues a decision is then made about the level of need. The levels are 'priority', 'severe', 'high', 'moderate' or 'low'. Your own views and those of the person you're looking after should also be taken into account when the assessment is carried out.

If the person you're looking after has priority needs in particular areas or severe needs in at least two, then NHS continuing healthcare should be provided. Someone can also qualify for NHS continuing care if they have a severe need in one area plus a number of other needs, or a number of high or moderate needs. In these cases the overall need, and interactions between needs, will be taken into account, together with evidence from risk assessments, in deciding whether NHS continuing healthcare should be provided.

Review

A case review should be carried out three months after the original decision, even if the person you're looking after did not receive a full assessment. Following that first review, further reviews should be carried out at least every year.

Making a complaint

Sometimes if you are unhappy about any services you have received or when things go wrong, you may want to complain. So where do you start? If you decide you want to make a complaint it's important to keep records of dates, times, names and conversations, etc. to help you.

Who can help you make a complaint?

Local Clinical Commissioning Groups (CCGs)

Walsall CCG have a complaints procedure on their website to enable you to share your feedback on your local NHS.

☎ 01922 618 388

💻 [Walsall CCG - Complaints](#)

NHS complaints Advocacy – Voiceability runs NHS Complaints advocacy service.

The service will enable you to understand what your options are and to get the best resolution for you. For further information to contact

☎ 0300 330 5454

💻 <http://www.nhscomplaintsadvocacy.org/>

Patient Advice and Liaison Service (PALS)

This service offers confidential advice, support and information on health related matters.

They provide a point of contact for patients, their families and their carers. You can find [PALS](#) in your local hospital.

Walsall Council

The council welcomes feedback on all services. If you are unhappy please tell us about it, we want to take prompt action to address your concerns.

☎ 01922 650 000

💻 [Walsall - Comments, compliments and complaints form](#)

📍 Walsall Council, Civic Centre, Darwall Street, Walsall WS1 1TP



Paying bills

If you have not set up direct debits or standing orders for all of your usual bills, now is a good time to do this. Ask your friends, family or Citizens Advice to help you do this. It will mean that you do not have to worry about your bills being paid on time and you won't forget to pay any of them. Direct debits or standing orders can easily be altered if necessary.

Section 6: Further information

If you require further information on dementia or the help that you might be able to get, see details below:

Ace Care Day Centre for Dementia

📍 New Road, Brownhills. WS8 6AT

☎ 01543 454 438

Advocacy Matters

☎ 0121 321 2377

💻 <http://www.advocacymatters.co.uk/>

Age UK Walsall

📍 10 The Bridge Walsall. WS1 1LR

☎ 01922 638 825

💻 <http://www.ageuk.org.uk/>

Alzheimer's Society

📍 Castle Mill, Burnt Tree, Dudley. DY4 7UF

☎ 0121 521 3020

💻 <http://alzheimers.org.uk/>

Apna Ghar – Day Care Centre

📍 Ford Street, Pleck, Walsall. WS2 9BW

☎ 01922 616 012

Attendance Allowance

☎ 0345 605 6055 (Monday to Friday 8.00 am – 6.00 pm)

💻 [Claim form](#)

Bereavement Counselling

📍 Globe House 3, Bradford Place, Walsall. WS1 3PL


☎ 01922 724 841

Blue Badge Scheme (apply via council)


 [Blue Badge Scheme](#)

Blind, Walsall Society for the

 Hawley House, Hatherton Road, Walsall. WS1 1XS

 01922 627 683 / 637 010

Care Quality Commission

 <http://www.cqc.org.uk/>

Care Act (carers' rights)


 [Carers Right Guide](#)

Carers Trust

 www.carers.org


Citizens Advice Bureau

 139-144 Lichfield Street, Walsall. WS1 1SE

 01922 700 600

 [CAB Walsall](#)

Community Continence Service


 01922 605 940 / 605 947

 continence.service@walsall.nhs.uk


Complaints

 Governance Department, Walsall CCG, Jubilee House, Bloxwich Lane, Walsall. WS2 7JL

 [Walsall CCG - Complaints](#)

 01922 618 388

NHS complaints Advocacy – Voiceability runs NHS Complaints advocacy service

 0300 330 5454

 <http://www.nhscomplaintsadvocacy.org/>

Walsall Council complaints

📄 Walsall Council, Civic Centre, Darwall Street, Walsall. WS1 1TP

☎ 01922 650 000

Dementia UK

💻 www.dementiauk.org/

Dementia Advisers

☎ 01922 707 898 / 01922 707 899

💻 advisers@ageukwalsall.org.uk

Dementia Cafés

☎ 07793 699 141

💻 [Dementia Cafes](#)

Dementia Support Worker : Hard to Reach Groups

☎ 07788 385 446

💻 Sadat.hussain@accordha.org.uk

Dementia Support Worker: Screening and Support

Support people who are not yet diagnosed and those with a diagnosis of dementia.

☎ 0121 521 3028

💻 charlotte.crane@alzheimers.org.uk

DVLA (Driving)

📄 Drivers Medical Group, DVLA, Swansea. SA99 1DF

💻 eftd@dvla.gsi.gov.uk

Dudley & Walsall Mental Health Partnership Trust

📄 Trafalgar House, 47 – 49 King Street, Dudley, West Midlands, DY2 8PS

☎ Switchboard: 0300 555 0262

💻 Email: bettertogether@dwmh.nhs.uk

Emergency Carers' Service

☎ 0121 505 7373

Family Guidance & Community Welfare

🏠 66 Lancaster Avenue, Aldridge, Walsall. WS9 8RQ

☎ 01922 452 213

Gadget Gateway, The

🏠 Independent Living Centre, 9 Wisemore, Walsall. WS2 8EZ

☎ 01922 650 790

💻 [The Gadget Gateway](#)

Independent Living Centre

🏠 9 Wisemore, Walsall. WS2 8EZ

☎ 01922 650 790

💻 ilc@walsall.gov.uk

💻 www.walsall.gov.uk/ilc

Lasting Power of Attorney

💻 <http://www.publicguardian.gov.uk/index.htm>

Mental Capacity

💻 <http://www.scie.org.uk/adults/mentalcapacity.asp>

Mindful Gifts

☎ 07828 935 451 or 01922 495 994

💻 <http://www.mindfulgifts.co.uk> / mindful.gifts@yahoo.com

NHS Choices

💻 <http://www.nhs.uk/Pages/HomePage.aspx>

NHS Local

💻 <http://nhslocal.nhs.uk/>

Older People's Mental Health Liaison Team

📍 Moat Road, Walsall. WS2 9PS

☎ 01922 721 172 / 01922 656 354

Power of Attorney

💻 <http://www.publicguardian.gov.uk/index.htm>

Social Care Institute for Excellence

💻 <http://www.scie.org.uk/>

Social Work Teams

Walsall Council

📍 The Civic Centre, Darwall Street, Walsall. WS1 1DA

☎ 0300 555 2922

Stan Ball Centre – offers support / activities for further details to contact the centre.

📍 Stan Ball Centre, Abbotts Street, Walsall. WS3 3BW

☎ 01922 403 351

St Gabriel's Day Centre

📍 Walstead Road, Walsall. WS5 4LZ

☎ 01922 647 025

St Giles (Palliative Care)

📍 Goscote Lane, Walsall. WS3 1ST

☎ 01922 602 540

Walsall Community Living Directory

💻 [See Web Directory](#)

Walsall Carers Centre

📍 The Crossing at St. Paul's, Darwall Street, Walsall. WS1 1DA

☎ 01922 636 663

☎ 01922 638 849 (Helpline)

Walsall Link Line

📍 St Catherine's with Chad's Church, Edison Road, Beechdale, Walsall. WS2 7HT

☎ 01922 6400 916 / 07742 917 766

💻 mandykeay@yahoo.com

Walsall Manor Hospital

📍 Moat Road, Walsall. WS2 9PS

☎ 01922 721 172 / 01922 656 354

Water Mill, The

Care Home – Older People with Dementia

📍 Goscote hospital site, Goscote Lane, Walsall. WS3 1SJ

☎ 0370 192 4220

Welfare Rights Service

📍 Walsall Council, 1st Floor Civic Centre, Darwall Street, Walsall. WS1 1XU

☎ 01922 652 250

💻 welfarerights@walsall.gov.uk

West Midlands Fire Service Free Home Safety Checks

Your safety is their concern. For further information please call the Freephone helpline.

☎ 0800 389 5525






💻 <http://www.wmfs.net/content/stay-safe>



Section 7: Frequently Asked Questions (FAQs)

Can dementia be prevented?

Whilst there are no specific measures that one can take to remove the possibility of developing a dementia, there is increasing evidence to suggest that leading a healthy lifestyle can help reduce an individual's risk and delay the onset of dementia. Follow these links to learn more about this:

-  [Maintain your brain](#) - USA awareness campaign
-  [Healthy Brain](#) - Alzheimer Society of Canada
-  [Good For Your Brain](#) - Campaign from Scotland
-  [Factsheet on genetics and dementia](#) - Alzheimer's Society
-  [Am I at risk of developing dementia?](#) - Alzheimer's Society

Can I be included in dementia research?

You should discuss this with your GP and the Memory Assessment Service. Some people do become involved in research but this is generally in the very early stages of dementia.

The Alzheimer's society has some information on their research programmes. Follow this link to find out more

-  <http://www.alzheimersresearchuk.org/>

Can I still go on holiday?

Yes, usually. You should discuss this with your GP and the Memory Assessment Service and if going abroad, make sure you have adequate insurance and your insurance company is aware of your dementia and is covering you for it.

Can you catch dementia?

No you cannot catch dementia.

Do people with dementia get depressed?

Yes people with dementia can get depressed and quite often their carers too. If there is a concern about this the person should make an appointment with their GP.

Do younger people develop dementia?

Yes younger people do develop dementia. This is known as early onset dementia, young onset or working age dementia and affects people under the age of 65 years of age. People can develop this from their 30s and 40s although this form of dementia only accounts for about 10% of all people who have dementia.

How is dementia diagnosed?

Dementia is diagnosed following a clinical assessment. In other words from the results of questions and tests the Memory Assessment Services carry out. It is usual to have blood tests to rule out physical causes of memory problems and sometimes a brain scan, which can help with diagnosis. Some people also have an ECG (heart trace) as part of this process.

How many people have dementia?

Statistics for dementia:

- 1 in 4 of people over the age of 85 have dementia
- 1 in 20 people over the age of 65 have dementia
- 40% of people aged 65 or over in acute hospitals could have an undiagnosed dementia
- 29% of carers of people with dementia in the West Midlands were found to have levels of depression
- In the next 13 years there will be a 38% increase in people with a likely dementia
- Young Onset Dementia is three times more prevalent in black and ethnic minority groups in the West Midlands
- 36% of people with Down Syndrome between the ages of 50-59 have dementia
- People who have any other Learning Disability are four times more likely to develop dementia
- Two thirds of care home residents have dementia
- More than two thirds of people believed to have dementia in Walsall have a diagnosis. This is around 2,000 people.

Is Alzheimer's disease inherited?

Most people who develop Alzheimer's disease do not have a family history. However, there are a small percentage of people who can develop Alzheimer's as a result of a family member. These often affect younger people and it accounts for about 5% of people who get Alzheimer's disease. Where there is a family history of stroke and vascular dementia, one might expect to see an increase chance of a family member going on to develop this form of dementia above the general population.

Is dementia a mental illness?

Not technically no, although mental health services are usually the people who run the Memory Assessment Services. Dementia is a disease of the brain and can be described as a syndrome.

Is dementia something older people get?

No. Not just older people, although being older puts you into the highest risk group for dementia. Dementia is not part of ageing.

Is there are cure for dementia?

No, there is no cure for dementia but research continues into this area. However, there are medications which can slow the deterioration and help to manage symptoms.

My mother/father has dementia... Will I get it?

Most people who develop Alzheimer's disease do not have a family history. However, there are a small percentage of people who can develop Alzheimer's as a result of a family member. These often affect younger people and it accounts for about 5% of people who get Alzheimer's disease. Where there is a family history of stroke and vascular dementia, one might expect to see an increase chance of a family member going on to develop this form of dementia above the general population.

Should I take vitamin B supplements?


There was some research where very high doses of vitamin B were administered, which appeared to benefit people with mild cognitive impairment (memory problems but not dementia). These doses were well above what is normally recommended and taken over the counter. You should discuss this with your GP and pharmacist.

Should I tell people about my diagnosis of dementia?

If you are diagnosed with dementia, do not try to cope with the emotional reactions on your own. Give yourself time to come to terms with the diagnosis and find out more about living with dementia. Talk to family and friends or your GP, who might suggest other organisations you can turn to for help and information.

What are some of the early signs of dementia?

- Poor short-term memory recall
- Disorientation in time and place
- Language difficulties
- Problems performing familiar tasks
- Decreased or poor judgement
- Mood changes
- Loss of initiative
- Misplacing things around the home
- Personality changes



For those people reading this document who are worried about their memory, see our, "Are you worried about your memory?" booklet.

What is dementia?

The term 'dementia' is used to describe the symptoms that occur when the brain is affected by specific diseases and conditions such as Alzheimer's disease and sometimes as a result of a

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

What is the difference between Alzheimer's disease and dementia?

Alzheimer's disease is a type of dementia and the most common. About 62% of all people who have dementia are diagnosed with Alzheimer's disease.

What was the memory test I was asked to take?

The test is one of a number of widely used tools to support making a diagnosis. Although this is a guide on how good someone's memory is, it is not diagnostic and the person asking the questions takes into account all sorts of other things too. It is less useful for people whose first language is not English, if someone has difficulties with sight or read and writing.

What other support is available?

There are a number of local services available such as dementia cafés, day centres, support workers, support groups, carers groups, etc. To find out what is available in your area consult the Walsall Community Living Directory:

 [See Web Directory](#)

Where can I find more help?

See our other dementia pages and the web links to further information:

 <http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200120>

Will I die from dementia?

Dementia is a terminal illness, so as a result of developing dementia, people eventually die. However, dementia is not always recorded as the cause of death and some cases not mentioned at all or as a contributing factor. As time goes on, the person's ability to cope with infections and other physical problems will be impaired due to the progression of the disease and one may die with a heart attack or bronchopneumonia. Dementia is life limiting but this is over a number of years. Whilst everyone is different, it is not unusual to live with dementia for more than ten years.

Will I have to go into a care home now that I have been diagnosed with dementia?

This is a very common concern and one which sometimes puts people off approaching their GP if they worry they might have dementia. Whilst in the more advanced stages of dementia some people struggle to look after themselves and decide they would be safer in a care home, every effort is made to keep people in their own homes. As the dementia progresses and people need more assistance, services can be put in place to help maintain as much independence as possible. This includes the use of assistive technology.

Notes

Notes

Notes

First published in 2011 by the Joint Commissioning Unit for NHS Walsall and Walsall Council.

This updated version has been developed with input from all of the organisations listed on the back page.

Disclaimer

This publication contains information and general advice. It should not be used as a substitute for personalised advice from a qualified professional. NHS Walsall Clinical Commissioning Group & Walsall Council does not accept any liability arising from its use. We strive to ensure that the content is accurate and up to date at the time of publication but information can change over time.

Feedback Form

Please use this form to suggest items for inclusion and to let us know about anything which you feel needs improving. Your opinion is important to us and will help to shape the next version of this document.

Comments:



* Please delete as appropriate

- | | | | |
|---|--|------|-----|
| 1 | Did you find this document useful? | Yes* | No* |
| 2 | Is the document easy to follow? | Yes* | No* |
| 3 | Do you understand more about dementia? | Yes* | No* |
| 4 | Would you recommend others read it? | Yes* | No* |
| 5 | Did you recommend it to others? | Yes* | No* |

Please return this form to:

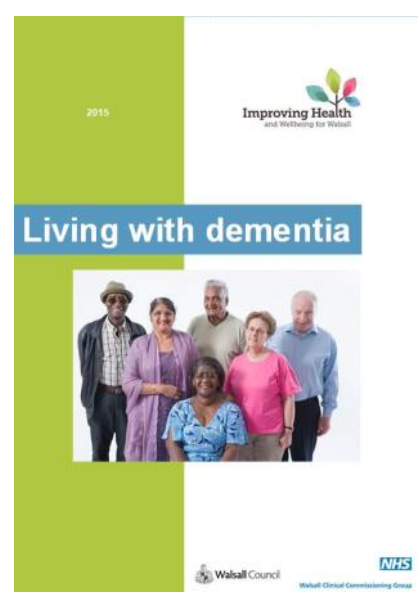
Commissioning Manager: Older People's Mental Health & Dementia

Joint Commissioning Unit for Walsall CCG & Walsall Council

Jubilee House, Bloxwich Lane

Walsall. WS2 7JL

 jcu@walsall.gov.uk



This document was first produced in 2011 by the Joint Commissioning Unit for Walsall CCG and Walsall Council. The following organisations have contributed to the 2015 version by taking part in a task and finish information sharing group.

