NHS
Walsall
Clinical Commissioning Group

2019 Edition

Living with Dementia

In Walsall

This is a guide to help you live with a diagnosis of dementia.

It describes how you can help yourself and where you can get help from others.

The guide contains lots of useful tips and explains where you can go for activity, support and information.

Please share this guide with your friends and family.

Improving Health
and Wellbeing for Walsall

Free Guide

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Where to go for help

Council

- Carer's assessment
- Help with personal care
- Community transport
- Occupational Therapy assessment
- Help to find day care and activity
- Concerns about neglect such as not eating and drinking/not looking after yourself
- Safeguarding concerns: To report concerns about different forms of abuse / vulnerability / potential harm
- Help with finding a care home

- Pathways4Life for dementia cafés, information and carer support
- Walsall Carers' Centre for carer support
- Citizen's Advice may help with benefits
- West Midlands Fire Service carry out home safety checks

GP

- Rapid deterioration or increase in confusion can be a sign of infection
- Falls
- Pain
- Unexplained symptoms
- Dehydration
- Constipation if over the counter medication has no effect
- Wounds or pressure sores
- High or low blood pressure
- Concerns about high cholesterol
- 12 month review of dementia care plan including carer
- 12 month health check for severely mentally ill (SMI)
- 12 month health check for learning disabilities
- To request a referral to the Dementia Diagnostic Assessment Service or Enhanced Community Mental Health Team for Older Adults
- To request a referral to learning disability services

Please turn over for more information

Out of hours ring 111 for advice or 999 in an emergency

Where to go for help

Mental Health

If under the care of mental health services or discharged less than six months ago, see below. If not currently under the care of mental health services or you were discharged more than six months ago, please see your GP first.

- Side effects of medication
- Concerns that dose of medication is too high or too low
- Hearing voices or seeing things others cannot see
- Delusions: Firm, fixed, false belief based on inadequate grounds not amenable to rational or paranoid thoughts
- Aggression (verbal and physical)
- Sleep disturbance
- Poor appetite
- Anxieties affecting normal activities
- Fears and phobias
- Thoughts about self harm and suicide (or speak to the Samaritans if you prefer)

Learning Disability

If the individual is under the care of the learning disability services, see below. If not, then referral can be via GP or self / relative / main carer / other professional directly to LD team at Orchard Hills House, Fallowfield Road, Walsall, WS5 3DY Tel: 01922 658800

- Commencement of medications and the monitoring of these – including side effects, dose amendments, protocols
- Aggression (verbal/physical)
- Behaviours that challenge
- Hearing voices or seeing things others cannot see
- Delusions
- Anxieties affecting normal activities
- Fears/phobias
- Mood disorders
- Sleep disturbance
- Changes with eating/poor appetite/drinking/swallowing
- Mobility deterioration
- Equipment for activities of daily living
- Support to arrange /attend health appointments

Out of hours ring 111 for advice or 999 in an emergency

Living with Dementia

This is a guide for people who have been diagnosed with dementia. A diagnosis of dementia is usually given by the Dementia Diagnostic 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.

Frequently Asked Questions (FAQs)

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 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

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 reading and writing.

How is dementia diagnosed?

Dementia is diagnosed following a clinical assessment. In other words from the results of questions and tests the Dementia Diagnostic 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.

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 the Alzheimer's Society to learn more about this:

💻 http://www.alzheimers.org.uk/factsheet/405

💻 http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=102

Can I be included in dementia research?

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

Alzheimer's Research UK 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 Dementia Diagnostic Assessment Service and if going abroad, make sure you have adequate insurance, 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, approximately 40% of 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.

Walsall has a talking therapies service that is particularly beneficial for carers. Carers of people with dementia tend to respond well to this type of intervention. People can self refer too:

☎ 0800 953 0995

💻 http://www.dwmh.nhs.uk/walsall-talking-therapies-service/

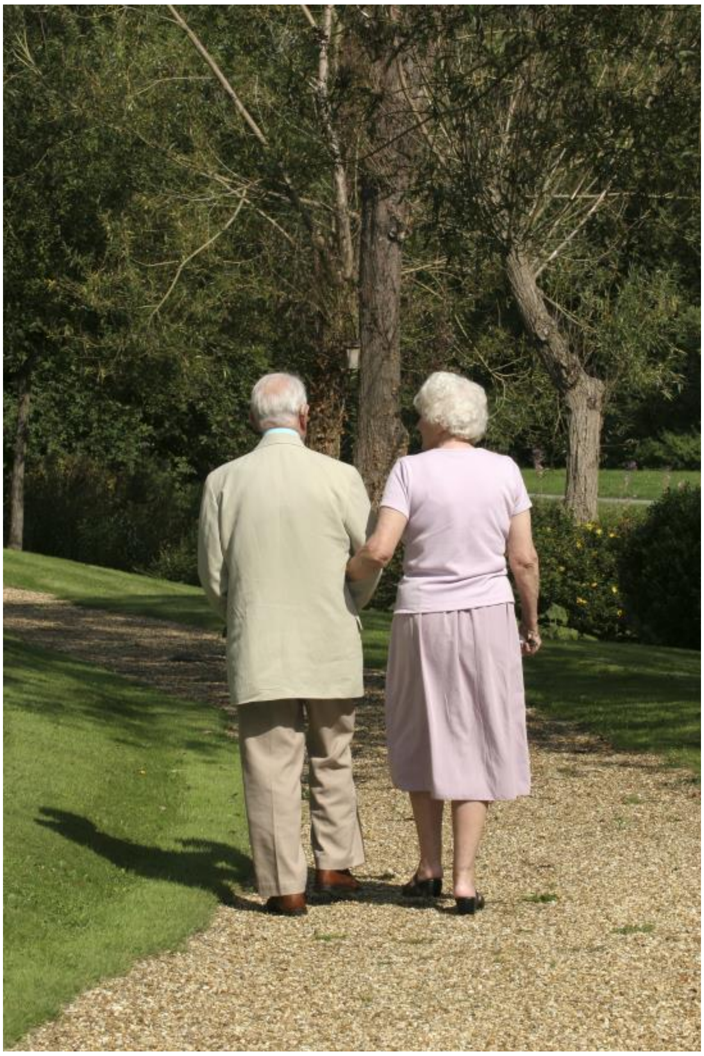
Do younger people develop dementia?

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 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 Dementia Diagnostic 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 supplements?

You should discuss this with your GP and pharmacist. However, published evidence contains the following advice:

B vitamin supplements

Taking B vitamin supplements probably has little or no effect on overall cognitive function at any time point up to five years and may have no effect at five to ten years.

Antioxidant vitamins: ß-carotene, vitamin C or vitamin E

The results are mixed, but the review authors say that long-term supplementation with antioxidant vitamins may be the most promising area for future research. There is low-certainty evidence of benefit in overall cognitive function with long-term supplementation with ß-carotene (after a mean of 18 years of treatment) and with vitamin C (after 5 to 10 years), but an antioxidant vitamin combination or vitamin E, alone or with selenium, may have no effect.

Selenium

Selenium alone, taken for around five years, may have no effect on the incidence of dementia.

Zinc and copper supplementation

Moderate-certainty evidence suggests that this has little or no effect on overall cognitive function, or the incidence of cognitive impairment, after five to ten years.

Omega 3-PUFA (fish oils)

There is no direct evidence of the effect of omega-3 supplements on the number of people being diagnosed with dementia, while three high quality randomised trials show no benefit for cognitive function, measured by the Mini Mental State Examination (MMSE) score at 24 or 40 months. Some people taking omega-3 supplements experienced mild gastrointestinal problems.

Vitamin and mineral supplements for people with mild cognitive impairment (MCI)

The authors of this Cochrane Review on the effects of vitamin and mineral supplementation on cognitive function in people with mild cognitive impairment (MCI) have found that the evidence is very limited. Only B vitamins have been assessed in more than one clinical trial. Taking B vitamins for six months to two years probably results in little or no difference in memory, thinking skills or quality of life, and the evidence doesn't tell us whether or not there are any harms from taking them.

They conclude: that, "*At the moment, it is not possible to identify any supplements which can reduce the risk of people with MCI developing dementia or which can effectively treat their symptoms.*"

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.

What treatments are available for dementia?

There are medications available for some types of dementia that may help to slow down the progression of symptoms and deterioration of memory. There is also a therapy called Cognitive Stimulation Therapy (CST) which research suggests can help in the same way as medication. CST also aims to increase people's confidence and self-esteem through focusing on their strengths and hobbies. CST is delivered through a programme of themed activities, carried out in weekly sessions. Each session covers a different topic and encourages participants to reminisce, use all their senses and most importantly laugh!

In Walsall people are offered a 14 week course of CST on diagnosis of dementia with the Therapy and Liaison Community Service (TALCS). Maintenance CST is delivered by the Personal Assistants: Dementia.

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 and the support of services.

Where can I find more help?

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

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

💻 http://www.wcld.co.uk/

Journey of Memory DVD

Journey of Memory was produced to raise awareness of dementia and help reduce the stigma surrounding mental health issues in the South Asian community. The DVD includes a short film about a grandfather's struggle with memory loss and the challenges he and his family face. It includes information and advice from health professionals about how to cope with dementia and where to go for help.

The DVD was produced by Dr Rashda Tabassum, an Old Age Psychiatrist for Dudley and Walsall Mental Health Partnership Trust. It can be used at dementia raising awareness events and can be distributed to the families who need more awareness and education.

Please contact Dr Tabassum for a copy of the DVD:

💻 rashda.tabassum@nhs.net

Alzheimer's Society

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

Alzheimer's Research UK

💻 https://www.alzheimersresearchuk.org/wp-content/uploads/2018/08/Support-booklet-for-WEB-290818.pdf

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 Dementia Diagnostic Assessment 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 Dr Arnold Pick, a Czech psychiatrist.

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 Dementia Diagnostic Assessment 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 when you are first diagnosed. They can signpost you to other longer term forms of support.

Personal Assistants: Dementia (PADs)

The Personal Assistants: Dementia (PADs) provide support for people who are newly diagnosed with dementia as well as their family members/carers. The PADs work alongside people for up to 12 weeks, providing access to information and services that will support the person with dementia to understand their diagnosis, feel supported and remain part of their community. The PADs will also work alongside carers and family members to ensure that they are supported to continue on in their caring role.

☎ 01922 725 509

💻 pads@accordgroup.org.uk

Dementia & Mental Health Advisor: Hard to Reach Groups

The Dementia & Mental Health Advisor: Hard to Reach Groups works with a variety of communities within Walsall to support people accessing information, services, signposting, memory screening and advice. This includes traveller communities, people with learning disabilities and people from black and minority ethnic (BAME) communities and also includes other individuals and communities who have difficulties in accessing mainstream services via traditional routes. This service provides community awareness raising and access to information and literature in a number of languages and formats.

☎ 07788 385 446

💻 sadat.hussain@accordha.org.uk

Carer Support

Dementia Support Workers

There is a monthly informal course run by dementia support workers from St Giles Hospice and Pathways 4 Life. The service is commissioned by NHS Walsall Clinical Commissioning Group. This is a four week course aimed at anyone supporting people with dementia to provide information for the future. It will cover areas such as information about dementia, infections, dementia related behaviours and planning for the future. Spaces are limited so booking is essential. To book your place please contact:

☎ Emily 0777 182 1351

☎ Pat 0778 838 5447

Walsall Carer’s Centre

If you look after a relative or friend of any age, who because of illness or disability, cannot manage without your help – then you are a carer. Walsall Carers’ Centre offers help and guidance to all carers. Their aim is to provide information on a whole range of services and to offer links to other sites that you may find useful.

☎ 01922 636663

💻 contact@walsallcarers.org

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.

Making Connections Walsall - Get Connected, Stay Connected

Are you lonely? Would you like someone to talk to?

Making Connections Walsall is a friendly service for older people in Walsall that aims to address loneliness and social isolation.

Making Connections Walsall tackles loneliness and social isolation by offering one-to-one support to help older people engage in community activities and build social networks, free of charge.

How does it work?

There are lots of groups, organisations and clubs in Walsall which can support the health and well-being of local older people. However, people often don’t know about them. Referrals are processed by the West Midlands Fire Service (WMFS) who will connect you to your local hub organisation.

The social connector will arrange to meet you, either in your home or at a community venue in your local area. At the first appointment they will discuss with you the types of activities you enjoy and will help you identify activities and projects available in your community.

Examples of available activities include reading groups, mobile library service, dementia cafés, keep fit, widow/widowers group, ballroom & sequence dancing, tea dancing, volunteering, bowling, arts and crafts, shopping services (for those who wish to do their own shopping), gardening, luncheon clubs, coffee mornings, mens’ sheds, knit and natter groups, adult education classes, befriending service (home visits and telephone).

Who is eligible?

People over 50 years old • Who live in Walsall • Who are lonely or socially isolated

To access the service:

☎ 0121 380 6690

💻 https://onewalsall.org/wp-content/uploads/2017/08/MCW-Service-Flyer.pdf

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 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. These can be paper based or digital.

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 and a digital calendar will do this for you. 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. Electronic appointment reminders are a helpful way to avoid these issues.

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. Electronic reminders using sensors can also do this and are relatively inexpensive.

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. People have been enjoying a virtual reality (VR) experience in Walsall for reminiscence, stimulation and fun. This can be a shared experience with younger members of your family so you can enjoy activities together.

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.

You can also buy useful daily living equipment to help you maintain a degree of independence.

Mindful Gifts is a social enterprise who might be able to help. They provide a unique shop (facility), set in the past, which provokes memories by utilising all the five senses, daily activities, social events, tea and cake, volunteer opportunities, moral support for carers and specialised activity products. The ‘not for profit’ shop is open Monday – Saturday, 10-6pm and is available to everyone.

For further information please contact Vicki Phipps:
☎ 01922 495 994

🖃 Mindful Gifts CIC, 1 Church Street, Darlaston, Walsall. WS10 8DS

💻 http://www.mindfulgifts.co.uk

💻 mindful.gifts@yahoo.com

Unforgettable is an online resource for purchasing assistive technology. Ask for a free catalogue.

☎ 020 3322 9070

💻 happytohelp@unforgettable.org

💻 https://www.unforgettable.org/

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.

This is Me

The Alzheimer’s Society and Royal College of Nursing created a document called, This is Me and can be downloaded for free.

This is Me provides an easy and practical way of recording who the person is. The form includes space for details on your cultural and family background; events, people and places from your life preferences, routines and your personality. It is suitable for use in any setting – at home, in hospital, in respite care or a care home and provides a valuable way of letting medical and social care staff know more about the person who has dementia.

The This is Me document lets health and social care professionals see the person as an individual and deliver person-centred care that is tailored specifically to the person's needs. It can therefore help to reduce distress for the person with dementia and their carer. It can also help to overcome problems with communication, and prevent more serious conditions such as malnutrition and dehydration.

💻 Download a copy of This is Me or type in the full address below:
https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/this_is_me.pdf

Message in a Bottle Scheme

What is it?

Its a simple idea designed to encourage people to keep their basic personal and medical details on a standard form and in a common location – the fridge!

What does it do? It saves the Emergency Services valuable time if they need to enter a property in an emergency situation. Not only does it help to identify who you are it also identifies if you have special medication or allergies. It is not only a potential lifesaver, but also it provides peace of mind to you, your friends and family by knowing that prompt medical treatment is provided and that the next of kin and emergency contacts are notified.

Who's it for? Anyone. Whilst it is focused on the more vulnerable people in a community, anyone can have an accident in the home, so this scheme can benefit anyone.

What does it cost? When ordering one bottle the scheme is free to the public and is funded usually by your local Lions Club.

Where can I get one? You may find the bottles displayed in your local GP's surgery, Local Pharmacy, Local Lions Club. If you have any difficulty locating a bottle please contact Lions Clubs Headquarters 0845 833 9502.

Who knows about it? All Emergency Services are aware of the 'Message in a Bottle' scheme, by displaying the green stickers in your home, the emergency services will locate the bottle in the fridge and use the forms inside to ensure you are treated quickly which can save time and save lives.

What's in the bottle? A form you fill in with your name, medicines, allergies & relatives contact details. And also two green stickers.

What do I have to do? Fill in the form, put it in the bottle. Put the bottle in your fridge. Put one green sticker on your fridge door and the other green sticker on the INSIDE of your house door.

Who co-ordinates the Scheme locally? Your local Lions Club. Many Lions Clubs across the Country take part in this project.

☎ 0845 833 9502

💻 MDHQ@lionsclubs.co

💻http://lionsclubs.co/MemberArea/where-can-i-get-a-bottle-from/

Apps

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?

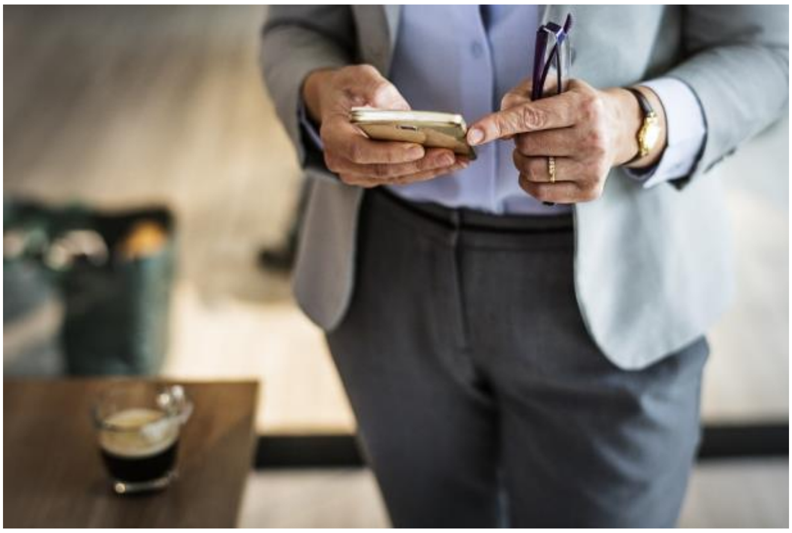
You access Apps through your smartphone, tablet or computer but you will need to be connected to the Internet to be able to do this. This could be through an Internet connection you may have in your home called ‘broadband’ (you usually have to pay for this) or through your mobile phone network usually 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.

Try using search terms like:

'dementia', 'tablet reminders' or 'memory training' to find suitable apps.

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. These two sites are called Facebook and Twitter.

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

You can get Attendance Allowance if you've reached State Pension age and the following apply:

- You have a physical disability (including sensory disability, for example 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 have needed that help for at least 6 months (unless you're terminally ill)

You must also:

- Be in Great Britain when you claim - there are some exceptions, such as members and family members of the armed forces
- Have been in Great Britain for at least 2 of the last 3 years (this does not apply if you're a refugee or have humanitarian protection status)
- Be habitually resident in the UK, Ireland, Isle of Man or the Channel Islands
- Not be subject to immigration control (unless you're a sponsored immigrant)

There are some exceptions to these conditions if you're living in another European Economic Area (EEA) country or Switzerland:

- If you're terminally ill
- If you're not expected to live for more than 6 months, there are 'special rules':
- There's no qualifying period for how long you've had your illness
- If you're eligible, you'll automatically get the higher rate of Attendance Allowance

If you’re in a care home

You cannot usually get Attendance Allowance if you live in a care home and your care is paid for by your local authority. You can still claim Attendance Allowance if you pay for all your care home costs yourself.

Assessment

You might get a letter saying you need to attend an assessment to check your eligibility. The letter will explain why and where you must go. At the assessment, you’ll be asked for identification. You can use a passport or any 3 of the following:

- Birth certificate
- A full driving licence
- Life assurance policy
- Bank statements

You cannot get Attendance Allowance if you already get Disability Living Allowance (DLA) or Personal Independence Payment (PIP).

Rate Level of help you need:

- Lower rate - £57.30

  Frequent help or constant supervision during the day, or supervision at night
- Higher rate - £85.60

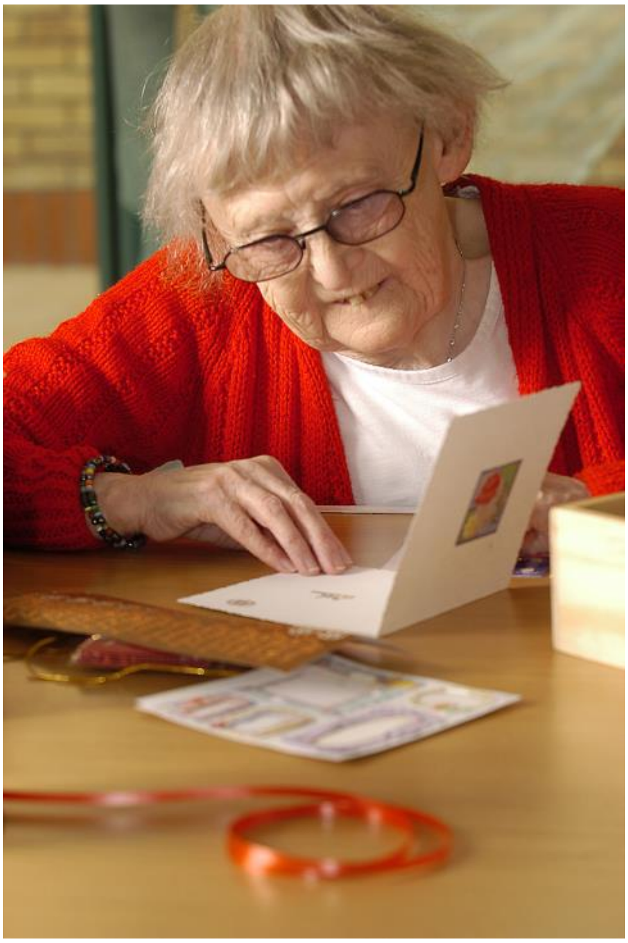
  Help or supervision throughout both day and night, or you’re terminally ill

The helpline for attendance allowance is:

☎ 0345 605 6055

(Monday to Friday 8.00 am – 6.00 pm)

💻 https://www.gov.uk/government/publications/attendance-allowance-claim-form



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 Dementia Diagnostic Assessment Service for advice.

Adult Social Care – What we do

Safeguarding of vulnerable adults and older people

We help adults with social care needs find care and support so they can live as independently as possible in their own homes.

We arrange adult social care support for:

- Adults with mental health needs
- Older people with physical or mental health needs including dementia
- 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
- The carers of adults and older people
- We can arrange for someone to work with you if you need help to understand what your needs are and how to access services you need.

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
- Identification of Preventative services that lead to regaining and retention of independence
- 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
- Allocation of personal budgets
- 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

Fax 01543 372947

Text phone 01922 654000

SMS text 07894114482

🖃 Walsall MBC, Adult Social Care, 3rd Floor, Zone 3D, Civic Centre, Darwall Street,
Walsall, WS1 1TP

💻 Ininitialintake@walsall.gov.uk

Walsall Community Living Directory

Walsall Community Living Directory - "A one stop web based directory of everything that's available within your local community"

In line with the Care Act (Information, Advise & Guidance) Walsall residents can now find out about local and national care and support services including what is going on in their local community, at touch of a button by accessing Walsall Community Living Directory.

The directory at: www.wcld.co.uk/ is managed by Adult Social Care. It provides an easy - to- search comprehensive directory of clubs, community, third sector and voluntary organisations, care providers, self-help groups and what is on listing of local events.

Individuals can search information under the key heading of:

Money Matters
Help to Live at Home
Housing Options
Things to do
Staying Safe
Caring for someone
Health and Well Being
Getting About
Education, Training and Employment
Product showroom
Personal Assistant Network
Online Self-Assessment
The Walsall Community Living Directory can be accessed via www.wcld.co.uk/:

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 equipment and/or adaptations that would benefit you. This may include assistive technologies.

Needs Assessment

A needs assessment is a chance for us to look at your social care needs and work with you to find out which services will best help you to maintain your wellbeing and independence. Your assessment is about **you**, and is completed together with the support of adult social services.

There is no charge for a needs assessment.

Social care needs will be based on things you may need help with, such as:

- Making sure you eat well
- Looking after yourself
- Being able to move around your home
- Being able to look after your home
- Having contact with family and friends
- Being able to access other community activities, such as work opportunities or education
- Emotional wellbeing and mental health
- Other caring responsibilities you may have
- Supporting your family and friends to care for you

What happens at a needs assessment?

Our assessor will visit you to talk about your needs and the services that can help you. You can have a carer, a family member or independent advocate with you at the visit.

We will offer your carer a carer’s assessment to find how out how much support and help they need to care for you.

If you agree, we may arrange a joint assessment with other agencies involved in your care, such as the health service.

Who is eligible for help?

Your needs assessment will look at all your needs and check whether any of them meet the national eligibility criteria for adult social care. We will use the national eligibility criteria to ask questions around the following areas:

- Managing and maintaining nutrition
- Maintaining personal hygiene
- Managing toilet needs
- Being appropriately clothed
- Are you remaining safe in the home
- Maintaining a habitable home environment
- Developing and maintaining family or other personal relationships
- Accessing and engaging in work, training, education or volunteering
- Making use of facilities or services in the local community including public transport and recreational facilities or services
- Carrying out any caring responsibilities you may have for a child

You will have eligible needs if you meet all of the following:

- You have care and support needs as a result of a physical or mental condition
- Because of those needs, you can't achieve two or more of the outcomes specified in your needs assessment
- As a result, there is a significant impact on your wellbeing

Together we will work out how much your independence and wellbeing is at risk if you do not have help.

What if I'm not eligible for help?

If you are not eligible for care and support from us, we will put you in touch with other organisations that may be able to help. Walsall Council works with partner agencies to ensure that relevant information and support can be readily available for those in need. You can find details of these organisations in our Community Living Directory.

What if I disagree with the assessor's decision?

Ask your assessor to explain their decision again so you are clear about the reasons for it. You can ask them to call again when you have someone there to support you if you want.

If you are still not satisfied, you can ask your assessor to reconsider their decision.

After that, you can ask for a second opinion.

If you are still not satisfied after the second opinion, you can make a complaint. See page 53.

Support Plans

What happens after my assessment if I am eligible for support?

If your assessment shows you are eligible for care and support, we will then tell you how much money you could get to pay for the care and support you need. This money is called a personal budget.

You will know up-front and early what your indicative budget is likely to be. This is so you can begin to plan and choose how your care and support needs can be met (with help if you need it).

Your personal budget can either be paid directly to you to enable you to manage your support (a **direct payment**) or you can have it managed by the council.

You may prefer to arrange your own care and support. You can receive your personal budget in the form of a **direct payment** to do this.

This means that you will be given the money to arrange your own care and support. Most people who receive care and support have a right to a direct payment.

There are some limited circumstances where a direct payment is not appropriate and an adult care worker will be able to tell you about these.

You must have arrangements in place to manage the necessary paperwork, either alone or with help. You will also need to satisfy the council that the services, which you intend to buy, will meet your assessed needs.

In addition, if you plan to employ staff, you will need to show that you will meet your legal requirements as an employer.

Employing a personal assistant is one option that can give you a more flexible and tailor-made package of support which suits you. Alternatively, you can choose to buy care and support from a service provider who is an agency or business that sells you care services, like care workers.

Your **support plan** will cover:

- What help you will get and who will provide it
- When help will start
- How often you will get help
- Contact details of the team who make sure you get help
- When reviews will take place to make sure we're still meeting your needs
- Details of care needs that can't be met and why
- What to do if you're unhappy with the service

Will I have to pay for care?

You may have to pay something towards the support we provide.

We will carry out a financial assessment in line with government guidelines to see whether you need to pay something towards your care and support. The amount you pay will depend on your capital, assets, income, savings and benefits.

What if my needs change?

We aim to review your needs every year. You can also ask us for a care review if your needs change.

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

The Stan Ball Centre offers fully supported Day care provision, Monday to Friday, from 9.30 - 3.30pm. Clients enjoy a warm and friendly welcome with access to a wide range of activities organised by our dedicated Activity Co-ordinator.

☎ 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.

☎ 0370 192 4993

🖃 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.

Activities at the Day Centre include:

- Music and Films
- Board games
- Arts and Crafts
- Reminiscence and Discussions
- Outings
- Cooked Lunches

☎ 01543 454 438

🖃 New Rd, Brownhills, Walsall WS8 6AT

💻 https://www.thebestof.co.uk/local/walsall/business-guide/feature/ace-day-care-services/86952/

Forget Me Not Café (Streetly Dementia Support Group)

This is a voluntary support group for those living with dementia, their carers and families living in Streetly.

🖃 Blackwood Methodist Church, Blackwood Road, Streetly, B74 3PL . Every 2nd Thursday in the month from 11am to 1pm.

☎ 0121 353 6140

💻 http://streetlydementiasupportgroup.weebly.com/

Walsall Link Line

Walsall Link Line is a voluntary organisation working across the borough providing services for older isolated people and those worried about their memory or living with dementia. They also provide support for carers and people living with mental health conditions; both adults and older adults.
They believe that everyone should have the opportunity to live life to the full through stimulating activity, friendship and fun. Their aim is to raise awareness and reduce stigma through work with children.

- Dementia Café St Catherine with St. Chad's Church, Edison Road, Beechdale, Walsall WS2 7HT. 1st Thursday each month 1pm – 3pm
- Dementia Activities Session St Catherine with St. Chad's Church, Edison Road, Beechdale, Walsall WS2 7HT. 3rd Thursday each month 1pm – 3pm
- Dementia Café Beacon Church, Collingwood Drive, Pheasey, B43 7JL. 3rd Tuesday each month 10.30am – 12pm
- Dementia Café Mattesley Court. Cresswell Crescent, Mossley, Bloxwich, Walsall, WS3 2US. 1st Wednesday each month 10am – 11.30am
- Dementia Café Mattesley Court. Cresswell Crescent, Mossley, Bloxwich, Walsall, WS3 2US. 4th Thursday each month 1pm – 2.30pm
- Dementia Den Walsall Link Line Centre, 6 Cavendish Gardens, Beechdale, Walsall WS2 7JN. Every Tuesday 10am – 11.30am
- Songs to Remember - Dementia St Catherine with St. Chad's Church, Edison Road, Beechdale, Walsall WS2 7HT. 3rd Wednesday each month 12.30pm – 2.00pm
- Carer Support Group Mattesley Court. Cresswell Crescent, Mossley, Bloxwich, Walsall, WS3 2US. 1st Wednesday each month 10am – 11.30am
- Carer Support Group St Catherine with St. Chad's Church, Edison Road, Beechdale, Walsall WS2 7HT. 2nd Thursday in February, May, August and November 6.30pm – 8.00pm
- Mind Matters (in partnership with Accord Age Matters and The Therapy and Liaison Community Service) for older people with depression and other mental health conditions St Catherine with St. Chad's Church, Edison Road, Beechdale, Walsall WS2 7HT. 2nd and 4th Thursday each month 10am – 12pm

🖃 Walsall Link Line Centre, 6
Cavendish Gardens, Beechdale,
Walsall WS2 7JN

☎ 01922 640 916 or
07742 917 766

💻 mandykeay@yahoo.com

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.

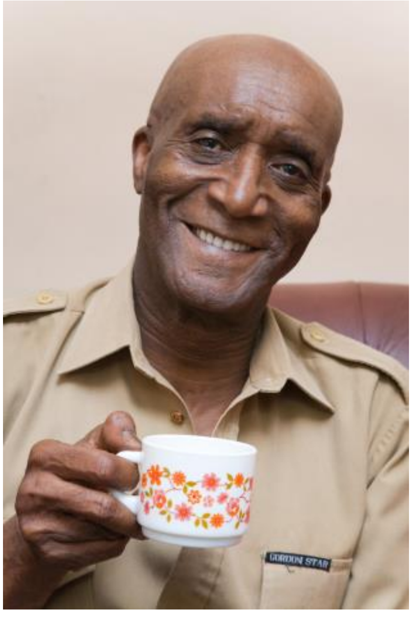
The dementia cafés are commissioned by NHS Walsall CCG and Walsall Council.

- Old Rectory Gardens, The Green, Aldridge, WS9 8UP. 4th Tuesday of the month 2-4 pm
- Community Engagement Centre, Ford Street, Walsall, WS2 9BW. 3rd Friday of the month 2-4pm
- Walsall Leather Museum, Littleton Street West, Walsall WS2 8EW. 1st Friday of the month 2-4pm
- Committee Room, Brownhills Park View Centre, Chester Road North, WS8 7JB. 3rd Wednesday of the month 2-4pm
- Willenhall Chart, 19 Gomer Street, WV13 2NS. 2nd Wednesday of the month 2.30-4.30pm
- Old Vicarage, Old Vicarage Close, Pelsall WS3 4AZ. 3rd Thursday of the month 6-8pm
- Furlong House, Lanton Close, off Kempthorne Gardens, Bloxwich, WS3 2LJ. 1st Wednesday of the month 2-4pm

Contact the organiser on:

☎ 07793 699 141

Memory Club



The Memory Club is for people with symptoms of cognitive impairment or living with dementia and their carers in an emotionally supportive atmosphere who wish to be as self-reliant as possible and will be managing with only intermittent assistance from others. It also works as a platform for others to understand dementia better and be able to better support their loved ones. Therefore a dementia or cognitive impairment diagnosis isn’t necessary to attend the club.

What is on offer?

The club offers stimulating group activities that are enjoyable and help build self confidence. Sessions are split into two segments: We relay information on a selected health condition that enables individuals to delay the onset of dementia or manage their condition better. For example, in Delves memory club, a practice nurse delivers an interactive presentation on health issues such as blood sugar, cholesterol, hyper tension, diabetes, depression, nutrition, communication with person with dementia, coping with challenging behaviour, medication management, assistive technology, summoning emergency help etc. The second segment covers a range of stimulating activities based on the attendees' preferences and abilities.

The memory clubs are free to attend and free refreshments are also provided.

- Delves Memory Club. Place of Refuge Community Church, Talke Rd, Delves, Walsall, WS5 4PH Monthly: Every 1st Tuesday of the Month 11-1pm
- Palfrey Memory Club. Milton St, Walsall WS1 4LA (Entrance: opposite Palfrey Infant School) Monthly: Every 2nd Tuesday of the Month 11-1pm
- Moxley Memory Club. Moxley People Centre, 3, Queen treet,Moxley,Wednesbury,WS10 8TA Fortnightly: Every 1st & 3rd Wednesday of the month 1.30pm-3.30pm

For further information please contact: Sadat Hussain, Dementia & Mental Health Advisor: Hard to Reach Groups

☎ 07788 385 446

💻 sadat.hussain@accordha.org.uk

Religious / Faith Communities

Some faith communities hold special events, support groups and services appropriate to the needs of people living with dementia – please check your local place of worship for details.

Respite stays

Respite involves going into a care 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:

💻 https://www.nhs.uk/Service-Search/Dentist/LocationSearch/3 (Find a dentist)

💻 https://www.alzheimers.org.uk/get-support/daily-living/dental-care (Leaflet)

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 the referral can be sent to email below.

☎ 01922 605 940 / 605 947

💻 continence.service@walsall.nhs.uk

Dementia Diagnostic 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 Dementia Diagnostic 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:

💻 https://www.gov.uk/blue-badge-scheme-information-council

Department for Work and Pensions – Looking for work if you are disabled or have a health condition

Support, advice and guidance for people of working age who are disabled or have long term/ complex health conditions – regardless of whether they are in receipt of benefits and who are looking to move into employment is available from the Department for Work and Pensions through Jobcentres located in Brownhills, Walsall and Willenhall. For further information please visit:

💻 https://www.gov.uk/browse/disabilities/work

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 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.

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.

If you are experiencing work-related difficulties because of their poor memory, speak to your GP. Your GP may suggest you discuss it with the Dementia Diagnostic Assessment Service who diagnosed you or a Personal Assistant: Dementia.

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.

Guidance from the DVLA for Professionals:

Group 1 car and motorcycle - May be able to drive but must notify the DVLA.

It is difficult to assess driving ability in people with dementia. The DVLA acknowledges that there are varied presentations and rates of progression, and the decision on licensing is usually based on medical reports.

Considerations include:

- poor short-term memory, disorientation, and lack of insight and judgement almost certainly mean no fitness to drive
- disorders of attention cause impairment
- in early dementia, when sufficient skills are retained and progression is slow, a licence may be issued subject to annual review.

A formal driving assessment may be necessary.

Group 2 bus and lorry - Must not drive and must notify the DVLA Licensing will be refused or revoked

The General Medical Council issued clear guidelines for doctors that are applicable to that 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 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.

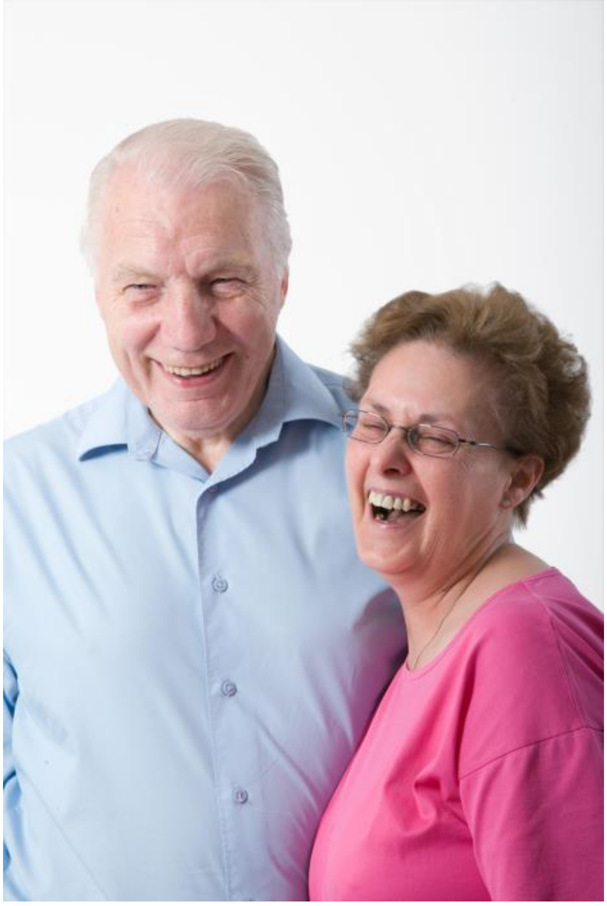
Who can make an LPA?

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:

💻 https://www.gov.uk/government/organisations/office-of-the-public-guardian

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.

Advance Care Plan

Advance care planning can help you to think ahead and prepare for the future. We all know what is important to ourselves and what we want and don’t want to happen but very often those closest to us aren’t aware of these wishes. Advance care planning allows you to talk about what is important to you and to write down what these priorities for care are at the end of life.

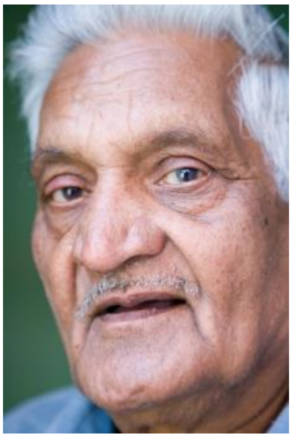
If for whatever reason in the future, you are unable to make a decision about your care, the wishes and preferences you have recorded in this document should be taken into account by those working in your best interests.

As advance care planning is about planning ahead, your priorities may change over time and you can change whatever you have discussed whenever you want to. If you have written down your discussions it is important that you review your plan regularly and discuss any changes with your doctor, nurse or social worker.

If you decide you would like to do this your health or social care professional will help you, but this is a record of your wishes and preferences and you should keep it and share it with anyone involved in your care.

In this country no one can legally request specific treatment however people can refuse certain medical treatments or interventions but this document is not meant to be used for such legally binding decisions. If you would like to discuss these issues in more detail we would recommend you seek the advice of you GP/Consultant or senior clinician who is involved in your care.

The advance care plan is not legally binding but it is designed to help you to think about the future and this represents your preferences and wishes which must be taken into consideration should you become ill.



You may wish to make changes to your Advance Care Plan, this is entirely normal as things change over time. To ensure that this document still represents your wishes, it is advisable that you review your plan at least every six months.

Remember to share any changes with your family, carers and professionals.

Specialist Palliative & End of Life Care Services (Walsall Healthcare NHS Trust) are provided at:

✉ Walsall Palliative Care Centre, Goscote Lane, Walsall. WS3 1SJ

✉ Walsall Manor Hospital, Moat Road, Walsall. WS2 9PS

For further information and advice, Monday to Friday 09.00-17.00

☎ 01922 602610

Preferred priorities of care (PPC)

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.

💻 http://www.dyingmatters.org/sites/default/files/preferred_priorities_for_care.pdf

Dementia is a terminal condition

Dementia is a terminal condition, 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.

This is what national palliative care organisations say about dementia being a terminal condition:

National Council for Palliative Care

Why is end of life care for people with dementia important? The number of people in the UK with dementia is increasing, with 1 in 3 people over the age of 65 now dying with dementia. Despite there being no cure, only 18% of people realise dementia is a terminal illness. Women are more likely to die with dementia than cancer.

Marie Curie

Dementia is a progressive neurodegenerative disease. This means that the symptoms become more severe over time. Symptoms usually include memory loss, confusion, speech difficulties, mood and behavioural changes and problems with self-care and other aspects of daily living. There are some treatments to alleviate the symptoms, but dementia is not curable and is a terminal illness.

Living arrangements

When first suspecting a diagnosis of dementia, people often put off going to see their GP because they are concerned than 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.

☎ 0800 148 8920

The Care Act

The Care Act 2014 strengthens the rights and recognition of carers in the social care system and came 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.

💻 https://www.carersuk.org/images/Help__Advice/CUK-Looking-After-Someone-2019WEB.pdf

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 Healthcare (CHC)

NHS Continuing Healthcare means a package of ongoing care that is arranged and funded solely by the National Health Service (NHS) where the individual has been assessed and found to have a ‘primary health need’ as set out in the National Framework for Continuing Healthcare revised October 2018.

There is a screening process with a Checklist followed by a full assessment of eligibility which help determine whether or not someone is eligible for NHS Continuing Healthcare.

Where can you receive NHS Continuing Healthcare?

You can receive NHS Continuing Healthcare in any setting (apart from acute hospitals) – including in your own home or in a care home. If you are found to be eligible for NHS Continuing Healthcare in your own home, the NHS will pay for your package of care and support to meet your assessed health and associated social care needs. If you are found to be eligible for NHS Continuing Healthcare in a care home, the NHS will pay for your care home fees, including board and accommodation.

Making decisions about who is eligible for NHS Continuing Healthcare

The process of assessment of eligibility and decision-making should be person-centred. This means placing you at the heart of the assessment and care-planning process.
It also means making sure that you have the opportunity to play a full role in the assessment process and receive the support to do this where needed. You could do this by asking a friend or relative to act as your representative and help explain your views.

The full assessment process for NHS Continuing Healthcare usually involves two steps: screening using the Checklist Tool, and a full assessment of eligibility using the Decision Support Tool.

Checklist outcomes

The checklist can be completed by a social worker or healthcare professional who is involved in the person’s care.

There are two potential outcomes following completion of the Checklist:

- a negative Checklist, meaning you do not require a full assessment of eligibility and you are not eligible for NHS Continuing Healthcare; or

- a positive Checklist meaning you now require a full assessment of eligibility for NHS Continuing Healthcare. It does not necessarily mean you are eligible for NHS Continuing Healthcare.

Assessment of Eligibility for NHS Continuing Healthcare using the Decision Support Tool

The Decision Support Tool will be completed by a multidisciplinary team (MDT) and will be led by the healthcare professional involved in the person's care.

Eligibility for NHS CHC is based on your needs, not on your diagnosis or condition. The Decision Support Tool collates and presents the information from your assessment of needs in a way that assists consistent decision-making regarding NHS Continuing Healthcare eligibility. The Decision Support Tool brings together and records your various needs in 12 'care domains', which are broken down into a number of levels.

The purpose of the tool is to help the multidisciplinary team assess the nature, complexity, intensity and unpredictability of your needs – and so recommend whether or not you have a 'primary health need'.

Once the assessment is completed it will be sent to Walsall Clinical Commissioning Group (CCG) who will ratify the decision made by the MDT and notify the person in writing of the eligibility decision.

Fast Track Pathway Tool

If you have a rapidly deteriorating condition which may be entering a terminal phase, then you may require 'fast tracking' to receive urgent access to NHS Continuing Healthcare. In the Fast Track Pathway there is no requirement to complete a Checklist or the Decision Support Tool. Instead, an appropriate clinician will complete the Fast Track Pathway Tool to establish your eligibility for NHS Continuing Healthcare. This clinician will send the completed Fast Track Pathway Tool directly to your CCG, which should arrange for a care package to be provided for you, normally within 48 hours from receipt of the completed Fast Track Pathway Tool.

Reviews

Continuing Healthcare eligibility is subject to review. You should normally have a review of your care package within three months of a positive eligibility decision being made. After this you should have further reviews on at least an annual basis. If the person's eligibility changes because their health needs have changed then a new assessment will be undertaken. If the person is no longer CHC eligible then social services will be notified as the person may be eligible for assistance from the Local Authority.

https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care

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

💻 https://walsallccg.nhs.uk/contact-us/complaints-procedure

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 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

Ace Day Care Services for Dementia

✉ New Road, Brownhills. WS8 6AT

☎ 01543 454 438

Advocacy Matters

☎ 0121 321 2377

💻 http://www.advocacymatters.co.uk/

Age UK

💻 http://www.ageuk.org.uk/

Alzheimer’s Society

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

☎ 0121 521 3020

💻 http://alzheimers.org.uk/

Attendance Allowance

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

💻 https://www.gov.uk/attendance-allowance/what-youll-get

Bereavement Counselling

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

☎ 01922 724 841

Blue Badge Scheme (apply via council)

💻 https://www.gov.uk/apply-blue-badge

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)

💻 http://www.carersuk.org/component/cck/?task=download&collection=file_list&xi=0&file=document&id=4711

Carers' Centre (Walsall)

☎ 01922 636663

🖃 Carers' Centre, 1st Floor, The Crossing at St Paul's, Darwall Street, Walsall. WS1 1DA
💻 https://walsallcarers.org/

Carer Training - Dementia Support Workers

Spaces are limited so booking is essential. To book your place please contact either Emily on:

☎ 07771821351 or Pat on: 07788385447

Carers Trust

💻 www.carers.org

Citizens Advice Bureau

🖃 139-144 Lichfield Street, Walsall. WS1 1SE

☎ 01922 700 600

💻 https://www.walsallcab.org.uk/

Community Continence Service

☎ 01922 605 940 / 605 947

💻 continence.service@walsall.nhs.uk

NHS Complaints

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

💻 https://walsallccg.nhs.uk/contact-us/complaints-procedure

☎ 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 Cafés

☎ 07793 699 141

🖳 http://www.ageuk.org.uk/brandpartnerglobal/walsallvpp/documents/scans@ageukwalsall_20140321_130222.pdf

Dementia & Mental Health Advisor: Hard to Reach Groups

☎ 07788 385 446

🖳 Sadat.hussain@accordha.org.uk

Driver and Vehicle Licensing Agency (DVLA)

🖃 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

🖳 http://www.dwmh.nhs.uk/

🖳 Email: bettertogether@dwmh.nhs.uk

Family Guidance & Community Welfare

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

☎ 01922 452 213

Forget Me Not Café (Streetly Dementia Support Group)

☎ 0121 353 6140

🖳 http://streetlydementiasupportgroup.weebly.com/

Lasting Power of Attorney

🖳 http://www.publicguardian.gov.uk/index.htm

Making Connections Walsall

☎ 0121 380 6690

💻 https://onewalsall.org/wp-content/uploads/2017/08/MCW-Service-Flyer.pdf

Mental Capacity

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

Message in a Bottle Scheme

☎ 0845 833 9502

💻 MDHQ@lionsclubs.co

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 England (Dementia)

💻 https://www.nhs.uk/conditions/dementia/

NHS Local

💻 http://nhslocal.nhs.uk/

Older People's Mental Health Liaison Team

Walsall Health NHS Trust,

🖃 Walsall Manor Hospital. Moat Road, Walsall. WS2 9PS

☎ 01922 721172 ext 6355

💻 opmhlt@walsall.nhs.uk

Specialist Palliative & End of Life Care Services (Walsall Healthcare NHS Trust)

For information and advice, Monday to Friday 09.00-17.00

🖃 Walsall Palliative Care Centre, Goscote Lane, Walsall. WS3 1SJ & Walsall Manor Hospital, Moat Road, Walsall. WS2 9PS

☎ 01922 602610

Power of Attorney

💻 https://www.gov.uk/government/organisations/office-of-the-public-guardian

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

St Giles Hospice

🖃 Walsall Palliative Care Centre, Goscote Lane, Walsall. WS3 1SJ

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 Giles Hospice (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

🖃 Walsall Link Line Centre, 6 Cavendish Gardens, Beechdale, Walsall WS2 7JN
☎ 01922 640 916 / 07742 917 766
💻 mandykeay@yahoo.com

Walsall Manor Hospital

🖃 Moat Road, Walsall. WS2 9PS

☎ 01922 721 172 / 01922 656 354

Water Mill, The

Day Care Centre – Older People with Dementia

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

☎ 0370 192 4993

West Midlands Fire Service Safe and Well Visits

Safe and Well visits are much more than just a free smoke detector. Our visits are carried out by operational firefighters, based at the West Midlands' 38 fire stations, and are expected to take no more than an hour. Fire crews will assess the risk of fire in the home. With the resident's agreement, they will also cover a range of issues and topics, including:

- weight, exercise and healthy eating
- mobility and falls
- mental health, memory loss and dementia
- loneliness and social isolation
- smoking, alcohol, medication and drugs
- hoarding
- employment
- road safety
- home security

A handbook complements the visits, providing information on safety, health and well-being. A copy will be left with the household, along with details of any actions or referrals made by the visiting fire crew.

It's important to us that we prioritise our Safe and Well visits for the most vulnerable members of the West Midlands community.

To help us do this, when we take your details, we operate a score based system to identify those who would most benefit from a visit from our fire crews. Unfortunately, this means that not everyone qualifies for a Safe and Well visit. Where this is the case, you will be sent a copy of the handbook given to residents and given general advice on safe placements for smoke detectors, which you would then need to purchase from a retailer and fit yourself.

🖳 https://www.wmfs.net/our-services/safe-and-well/#safewellwhatsinvolved

🖳 https://www.wmfs.net/our-plan/prevention/

☎ 0800 389 5525

Young Dementia UK

Young Dementia UK is the dedicated national charity for younger people with dementia and their families.

Over 42,000 people diagnosed with dementia in the UK are aged between 30 and 65. It is a life-changing condition to have at any age, but when you are younger and believe you have a long and full life ahead of you, the impact is significantly different.

💻 https://www.youngdementiauk.org/

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

This 2019 updated version has been developed with input from 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 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, contact details and services will 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*

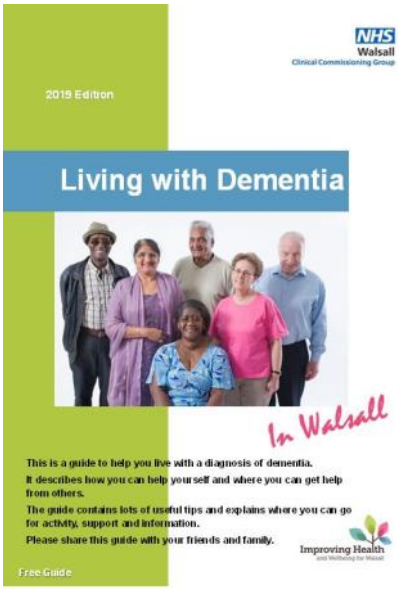
Please return this form to:

Head of Older People and Dementia

Walsall Clinical Commissioning Group

Jubilee House, Bloxwich Lane

Walsall. WS2 7JL



NHS
Walsall
Clinical Commissioning Group

2019 Edition

Living with Dementia

In Walsall

This is a guide to help you live with a diagnosis of dementia.
It describes how you can help yourself and where you can get help from others.
The guide contains lots of useful tips and explains where you can go for activity, support and information.
Please share this guide with your friends and family.

Improving Health
and Wellbeing for Walsall

Free Guide

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 2019 version. Living with Dementia is edited and published by NHS Walsall Clinical Commissioning Group.

NHS
Walsall
Clinical Commissioning Group

Improving Health
and Wellbeing for Walsall

Walsall Council

Dudley and Walsall NHS
Mental Health Partnership NHS Trust

NHS
Black Country Partnership
NHS Foundation Trust

Walsall Healthcare NHS
NHS Trust

UNIVERSITY OF
WOLVERHAMPTON

Forget Me Not Group

Pathways
4Life

Accord
are and Support

St Giles
Hospice Care

Mindful
Gifts CIC
Thought about gifts for cared about people

Walsall
Link Line

WEST MIDLANDS FIRE SERVICE

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