

Living Well with Dementia

the Westminster Guide



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Essential Reference & Directory

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Dementia Adviser and Lee Sims, Tresham
Dementia Services.

Housing 21 would like to thank all the people
who have contributed to the compilation of
this guide.

Foreword



I am delighted to introduce this guide. As a member of the post war baby boom my generation is probably better informed of the consequences of old age than any other. Life now begins at 60, not 40.

I have been a Westminster City Councillor for 20 years, and in 2009 I was the Lead Member of a review that produced a comprehensive report into our dementia services in Westminster. I also work as a Pensioner Liaison Officer for a large oil company and annually visit 400 pensioners over the age of 65 in the Greater London area who are all in varying states of health, some with dementia.

Scarcely a day goes by where there is not a press report or television programme about the problems encountered by people with dementia. In many cases they and their families suffer in silence blaming advancing years until a serious crisis presents itself. But suffering need not be a consequence if appropriate services are available. Early diagnoses from services such as the Westminster Memory Service are essential. Specialist day centres and respite services enable carers, particularly if they are a close relative, to have a break.

This detailed guide has excellent sections on all the issues which will concern anyone who has been diagnosed as having dementia – summed up with ‘the good news is that whatever your question, someone will help you to find an answer to it’. This is vital information for family, friends and professionals who have to care for someone who has been diagnosed with dementia and is an invaluable source of useful contacts and I commend its wide circulation.

Frances Blois

August 2010

Introduction

About this guide

Welcome to the Westminster Dementia Guide. It has been written to give an overview of the services and support available in Westminster to anyone with a diagnosis of dementia, as well as their family and supporters.

The guide has been designed to be used at any stage of dementia and offers a wide variety of information, as well as suggestions about where you may be able to get more support if you need it.

Receiving a diagnosis of dementia affects people in different ways. Some people feel the condition is inevitable with age and so needs little thinking about, whilst others begin to find new motivation to get on with their life and plan for their future. Some people feel relieved to know what is wrong, whilst others become fearful and worry about what might happen to them and how they are going to cope.

Whatever the response and feelings associated with the diagnosis, there will always be a number of questions that people want answers to. Some questions may be immediate, whereas others will crop up over time. Some of the answers may be very simple, and some may be more personalised and depend on a number of factors.

The good news is that whatever your question, we will be able to help you to find an answer!

Frequently asked questions include:

What is dementia?

(see page 6)

How will dementia affect me?

(see page 8)

Is there any support for my family?

(see page 34)

What services are out there to help me?

(see page 11)

What benefits are me or my family entitled to?

(see page 15)

Are there things I can do to help myself?

(see pages 14, 20 and 23)

What will happen to me when I can no longer care for myself?

(see pages 26 and 36)

Am I able to take any anti-dementia drugs to cure or help my condition?

(see page 14)

What financial decisions do I need to make now so my wishes are considered in the future?

(see page 16)

Will I lose my independence?

(see page 26)

How the guide works

It provides useful information to help you understand what a diagnosis means, and information to help people maintain independence and live well. It also explains the services and support networks available in Westminster, and their different roles and responsibilities.

The guide complements other local information for older people, such as Forward from 60, and the Resource Directory for Older People in Westminster.

To make the guide easy to use it is divided into colour coded sections. You may find you want to read one section at a time, or flick to specific areas of interest. At the end of each section there will be a Useful Contacts box with the telephone numbers of the agencies mentioned in the main text, or the details of other appropriate agencies.

If you are in any doubt, contact the Dementia Adviser on 0370 192 4265 (Monday to Friday 9am-5pm) who will be happy to help.



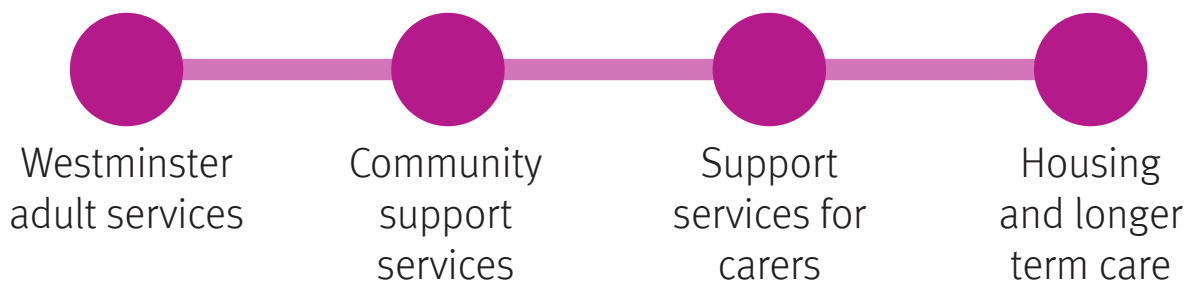
Section 1: Understanding dementia



Section 2: Living well



Section 3: Care services and support networks



Section 1: Understanding Dementia

1.1 What is Dementia?

Dementia is not a disease or illness in itself. It is a term used to describe a broad range of signs and symptoms which involve a decline in a person's mental ability. This decline is usually the result of damage caused to the brain by specific brain diseases, or by brain cells wearing out at a faster rate than would be expected in normal ageing.

Dementia is a progressive and degenerative illness, which means the symptoms will get worse over time. As brain cells are damaged or lost, people with dementia find day to day life becomes more difficult. They may develop problems with:

- Remembering things in the short term (short term memory).
- Making rational judgements.
- Communicating.

Facts and figures

An estimated 700,000 people in the United Kingdom have a type of dementia. In Westminster we estimate there are 1,700.

As people live longer the number of people with dementia is set to increase. By 2050 there will be over 1.5 million people with dementia in the UK, and 2,567 in Westminster.

Although there is no cure for dementia at the moment, there are a number of drugs that can slow down the progress of some forms dementia and improve people's quality of life. Other treatments such as person-centred care, psychological therapies and arts in dementia care can also help significantly.

Dementia affects both men and women. Statistically, more women than men have dementia, but this is because women tend to live, on average, five years longer. For example, Alzheimer's is most likely to start at around the age of 80, so because women tend to live longer than men, more women are likely to be diagnosed with this disease.

Types of Dementia

Alzheimer's disease

This is by far the most common cause of dementia. In Alzheimer's the cells of the brain die off at a faster rate than in normal ageing, and there is significant shrinkage in brain tissue. Alzheimer's tends to affect cells across the brain as opposed to a specific area, so over time the person will tend to experience a range of difficulties.

Vascular dementia

This is the second most common form of dementia and is caused by problems with blood flow to the brain. If the blood supply to the brain is impaired in any way brain cells die, causing symptoms of vascular dementia. Vascular dementia tends to appear suddenly (perhaps coinciding with a stroke). The person may then go through a period of relative stability before experiencing any further decline. This progression of the illness is often described as 'step like'. Whereas Alzheimer's disease affects all of the brain, Vascular dementia tends only to affect specific areas of the brain.

Dementia with Lewy bodies (DLB)

This form of dementia shares characteristics with both Alzheimer's and Parkinson's diseases and accounts for around four per cent of all cases of dementia in older people. Lewy bodies (named after the doctor who first identified them) are tiny, spherical protein deposits found in nerve cells, which disrupt the brain's normal functioning. They are also found in the brains of people with Parkinson's disease. Some people who are initially diagnosed with Parkinson's disease later go on to develop dementia that closely

resembles DLB. In general, DLB progresses at about the same rate as Alzheimer's disease, typically over several years.

Fronto-temporal dementia

Fronto-temporal dementia is a rare form of dementia. The term 'fronto-temporal dementia' covers a range of conditions, including Pick's disease, frontal lobe degeneration, and dementia associated with motor neuron disease. It is caused by damage to the frontal lobe and/or the temporal parts of the brain – the areas which are responsible for our behaviour, emotional responses and language skills.

Other less common causes of dementia

Other examples of related illnesses, conditions or diseases in which dementia can sometimes occur (usually during the later stages) include:

- CJD (Creutzfeldt Jacob Disease)
- Huntingdon's Disease
- HIV related dementia
- Motor Neuron Disease
- Downs Syndrome
- vCJD
- Korsakoff's.

What are the symptoms of dementia?

Although dementia is the result of a neurological impairment, no two people will share the same set of symptoms. A person's personality, their past, their state of health, as well as the environment in which they live are just some of the factors which will affect the symptoms they experience.

The most common signs and symptoms of dementia include:

- **Memory loss** – People with dementia have particular problems with short term memory and can often forget things they have just said or done. The capacity to remember events further back in time (long term memory) usually stays intact until the later stages of dementia.
- **Disorientation** – People with dementia often become disorientated and confused regarding the time of day, month or year, where they are, or how to navigate themselves around familiar settings.
- **Difficulties in performing familiar tasks or movements** – People with dementia may reach a stage where they are unable to start or complete everyday tasks. For example, this may include getting washed and dressed, or making a cup of tea or coffee.
- **Language difficulties** – People with dementia often find it difficult to find the correct word to say, or may substitute inappropriate words during a conversation.
- **Difficulties with perception (interpretation of the world)** – The ability to 'make sense of the world' is often distorted with dementia. Although a person's eyesight may be good, the brain's ability to accurately interpret what is being seen may be impaired, resulting in confusion and disorientation.
- **Poor or decreased judgement** – In dementia the specific areas of the brain responsible for making judgements and decisions can be affected. These changes result in a decreased ability to reason, plan and organise even simple everyday tasks.
- **Difficulties with abstract thinking** – Dementia can affect people's ability to think in an abstract way. For example, calculations that might once have been easy may now seem impossible. This is because dementia affects the person's ability to remember what numbers are, and how to use them.
- **Loss of initiative** – People with dementia may become more passive over time and lose interest in the activities or hobbies they previously enjoyed.
- **Changes in behaviour** – At some stage the decline in mental abilities may be accompanied by changes in behaviour. Dementia can cause people to become confused, suspicious or withdrawn, as well as fearful and aggressive. These changes in character and the resulting behaviour are sometimes referred to as 'challenging behaviour'.

Any change in personality or behaviour can be distressing for the person with dementia, as well as those supporting them. There are a number of things that can be done to support these psychological changes and these are discussed in the next section of this guide.

1.2 Diagnosis

Why is diagnosis important?

People experiencing memory problems often put off seeking help and support. Sometimes this is because they are embarrassed, or frightened. Or they may just feel that ‘forgetting things and getting confused’ is a normal part of getting older, so there is nothing which can be done.

It is important to get a proper diagnosis of dementia, not least to eliminate other – treatable – conditions, such as urinary and chest infections. It will also rule out other possible causes of confusion, such as poor sight or hearing, emotional changes and upsets (for example, moving home or bereavement) or even the side effects of certain drugs or a combination of drugs.

A proper diagnosis is important as it will:

- help people to plan for the future
- help people to get the right support services
- identify the type of dementia. As research develops, more drugs for treating different types of dementia become available, and it is important to match the dementia to the right type of drug. See page 14 for more information.

Sections 2 and 3 of this guide give information about the different agencies and organisations in Westminster that provide support to anyone who has been diagnosed with dementia, their carers, family and supporters.

How is a diagnosis made?

In the first instance, most people visit their GP. If your GP suspects you may be suffering from a dementia illness you will be referred for a proper dementia assessment by a specialist team. Usually you will be referred to the Westminster Memory Service, or perhaps one of Westminster’s Community Mental Health Teams. People under the age of 65 may be referred to the Young Onset Dementia Service.

The importance of an early diagnosis

Early diagnosis also means that someone with dementia will get the help and support they need at the earliest possible stage, to help them live independently in their own home for as long as possible. A support care package will give them information and guidance on how to manage their symptoms.

Equally, an early diagnosis gives someone with dementia the opportunity to think about their future care options, and consider financial planning and Advance Directives. Section 1.4 of this guide covers some of these issues.

Mild Cognitive Impairment (MCI)

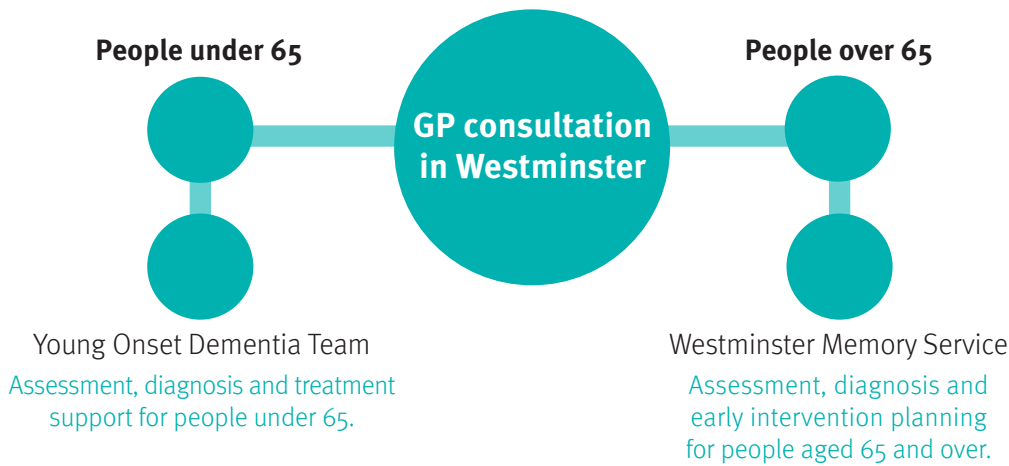
Many people who are assessed for dementia are diagnosed with a mild cognitive impairment, as opposed to dementia itself. Whilst MCI is not a form of dementia, the person being diagnosed may experience a number of the symptoms associated with dementia, and some will go on to develop dementia in their lifetime.

Later diagnosis

Being diagnosed with dementia when the illness is in its later stages does not necessarily mean doom and gloom. Although it may not be possible to receive drug therapies at this stage, there is still help on hand to provide the support and information people need.

Diagnostic services in Westminster

Westminster has a number of health professionals who are involved in the diagnosis and treatment of dementia illnesses. The diagram below shows the referral pathways.



Young Onset Dementia Service

The Young Onset Dementia Service is a team which specialises in helping people under the age of 65 with dementia in Westminster and Kensington & Chelsea. Based in St. Charles Hospital near Ladbroke Grove, the team includes doctors, social workers, an occupational therapist, a dementia specialist nurse, psychologists and other therapists.

The service includes information and advice, pre/post diagnostic counselling, investigations and diagnosis, assistance with practical and social needs and specialist day hospital support. Support is offered both in people's homes and at a weekly clinic.

The team aims to help younger people with dementia to live independently for as long as possible and help them manage their symptoms. They also provide support to carers, and will help find respite care and day care.

 **020 8206 7110** or **020 8206 7116**

Westminster Memory Service

The Westminster Memory Service is a team of specialists who will offer a comprehensive assessment of a person's memory abilities. After an assessment they will be able to offer a wide range of support. The team consists of a consultant psychiatrist, specialist doctor, psychologist, social worker, occupational therapists, a dementia nurse specialist and a dementia adviser. The Dementia Adviser Service is part of the Westminster Memory Service. For more information see page 11.

 **020 7612 1663**

1.3 Getting information and advice

Westminster's advice, information and guidance network

Westminster offers a number of services to provide advice, information and guidance to people with dementia, and their families. Some of these services are specific to Westminster, while others cover larger areas or are national organisations. Although all of the services have specific functions they provide advice, information and guidance across a broad range of topics.

- Admiral Nurses **0845 257 9406**
- Advocacy Plus **020 7439 3131**
- Alzheimer's Society **0845 300 0336**
- Carers Network Westminster **020 8960 3033**
- Counsel & Care **0845 300 7585**
- Dementia Adviser Service **0370 192 4265**

The Dementia Adviser Service (DAS)

The Westminster Dementia Adviser Service provides advice, information and guidance to people with dementia who live in Westminster, and their carers, relatives and supporters. It can provide practical information on living well with dementia, as well as detailed information on local and national services which offer support to people with dementia.

The Dementia Adviser Service is part of the Westminster Memory Service. It has an outreach focus, and can visit people who are living alone and/or who are housebound. You may be referred to the Dementia Adviser Service by the Memory Service team, or you may contact them independently. Six Steps Forward is a series of free seminars run by the Dementia Adviser for carers of people with dementia. See carer support on page 34

 **0370 192 4265**

Older People's Community Mental Health Teams (CMHT)

There are two Community Mental Health Teams that provide specialist ongoing assessment and support to people over 65. Although the work of the CMHT is not exclusive to people with memory problems or dementia, the team will have several types of workers with different knowledge and skills. Staff work closely together to offer support, encouragement and practical help to their clients, and each client is assigned a key worker to be their main point of contact.

Based in the north and south of Westminster, the CMHTs work at different venues, including GP surgeries, outpatient clinics, day centres, hostels, and people's own homes.

 **020 7641 1175**

Carer's Network Westminster

Carer's Network Westminster offers local support groups and training activities for carers who support someone living in Westminster. The Network is affiliated to the Princess Royal Trust for Carers and supports carers across all care groups, including carers of people with dementia.

 **020 8960 3033**

 www.carers-network.co.uk

 info@carers-network.co.uk

Westminster's Senior Passport

The Senior Passport is a general information service for older people living in Westminster. The service offers help and guidance to make it easier for older people and their carers to access council services, health services offered by NHS Westminster, and social and community activities.

 **020 7641 1444**

 www.westminster.gov.uk/services/healthandsocialcare/adultservices/older

Admiral Nurses

Admiral Nurses are mental health nurses who specialise in helping people with dementia and their families from the point of diagnosis. They are skilled at assessing the needs of people with dementia, as well as the needs of their families and carers. Admiral Nurses work in the community and other settings and they provide information and practical advice, emotional and psychological support, and guidance about accessing services.

 **020 8206 7133**

Age UK

Age UK is a national charity (formerly Age Concern and Help the Aged). Westminster Age UK offers a number of specialist advice and home support services for older people. You can contact their Information and Advice Team by telephone, or by visiting their drop-in advice centre. There are three community hubs in Westminster: one in Maida Vale and two in Covent Garden which are open Monday to Friday and offer a wide range of activities, support and social interaction.

Age UK also has a free national advice line that is open from 8.00am to 7.00pm every day of the year. The charity also publishes a range of books, factsheets, and guides.

 **020 7724 6930**

 www.acwestminster.org.uk

 enquiries@acwestminster.org.uk

Counsel and Care

Counsel and Care is a national charity working with older people, their families and carers. They provide personalised, in-depth advice and information on care and support to people over 60. They specialise in issues about community care and vulnerable older people, such as staying in your own home, moving into a care home and paying for care. They produce over 50 information guides and factsheets about the most common issues affecting older people.

 **0845 300 7585**

Alzheimer's Society

The Society provides reliable and up to date information to help with every aspect of living with dementia: from understanding your diagnosis and assessment, to dealing with the financial challenges you may encounter. The Society produces more than a hundred free factsheets about dementia which answer many of the most common questions, and they publish a monthly magazine as well as brochures and leaflets.

The Alzheimer's Society also runs a number of other services. Their National Dementia Helpline is a confidential service, and callers will speak to trained advisers who can provide information, support and guidance. The Society also runs Talking Point – an online support and discussion forum for anyone affected by dementia.

 **Alzheimer's Society
National Dementia helpline
0845 300 0336**

 www.alzheimers.org.uk

Citizens Advice Bureau

Although the Citizens Advice Bureau does not offer a specific service to older people, or people with dementia, it offers free, independent and confidential advice and can help with a range of issues. For example, advising on matters such as housing, welfare benefits, legal matters and money problems.

There are two offices in Westminster – one in Pimlico, the other in Paddington. To avoid having to wait it is best to ring and make an appointment. They also offer a telephone enquiry line.

 **0844 477 1611**

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

1.4 After diagnosis – things to think about and legal matters

So, is treatment possible?

Dementia drugs

In recent years a number of drug therapies have been developed to slow down the progression of Alzheimer's disease. These drugs are known as anti-dementia drugs and include:

Donepezil (Aricept)

Galantamine (Reminyl)

Rivastigmine (Exelon)

Ebixa (Memantine).

All of these drugs can temporarily slow down the progress of symptoms in people with early to moderate stages of the disease. The use of the drugs on the NHS has been restricted to this group following a review by the National Institute for Clinical Excellence (NICE).

Exelon is used for the treatment of dementia associated with Parkinson's disease.

Ebixa is a newer drug which is thought to benefit those in the moderate to severe stages of Alzheimer's disease. Whilst these drugs may slow down the progression of Alzheimer's disease, every person will respond differently and the affects can vary considerably from person to person.

There are also drugs to help treat and reduce depression, challenging behaviour and agitation. However, no drugs should be given to a person with dementia without discussion with their GP, and in some cases with their consultant psychiatrist.

Non-drug treatment

The maintenance of general good health is important and people often respond well to activities that stimulate cognition, such as reminiscence, music therapy, gardening and art. People with vascular dementia may be able to reduce the risks of further strokes through changes in lifestyle, such as a healthier diet and regular exercise. Diet and exercise can also help prevent depression.

Once someone has had a diagnosis there are some practical things to think about and consider for the future. It is best to try and be open about the diagnosis and let those closest know as soon as possible, so that family and friends can understand and provide the right sort of support.

Practical things to think about

Work

If the person with dementia is still at work, they might be finding it increasingly difficult to cope. It will be worthwhile considering opportunities to decrease their hours, or take a less demanding job, or think about when it might be appropriate to leave work altogether.

At this point it will be important to get advice on pension rights, and what is due to them, as well as checking to see what benefits they and their family are entitled to.

Driving

A diagnosis of dementia is not in itself a reason to stop driving. What matters, from both a legal and a practical point of view, is whether or not an individual is still able to drive safely. Many people with dementia retain learned skills and are able to drive safely for some time after diagnosis. However, as dementia progresses a person will eventually lose the ability to drive. The stage at which this happens will be different for each person.

If a person with a diagnosis is unsure of their ability to continue driving, they can take a driving assessment. To do this, they need to apply directly to an assessment centre, and pay a fee. An assessment is not like a driving test. It is an overall assessment of the impact that the dementia is having on a person's driving performance and safety, and it makes some allowances for the bad habits that drivers get into.

Anyone who drives and has a diagnosis of dementia must inform the DVLA.

The insurance company must also be asked whether the person with dementia is still covered.

DVLA

 **0870 240 0010**

Welfare benefits

There will be financial implications as the needs of the person with dementia change. This may be because the person with dementia has given up work, or because they need greater physical care and support.

Some of these benefits will be for the person with dementia and others will be for their carers, and some are available irrespective of income. Attendance allowance is an example of a payment that goes to the person with a disability. Getting the right benefits can make a difference to people. However, our benefits system is so complex, and changes so often it can get very confusing, but Age UK Westminster and Westminster Citizens Advice can provide information and support on claiming benefits.

The Benefit Enquiry Line provides confidential advice and information for people with disabilities and their carers and representatives about social security benefits and how to claim them.

Benefits Enquiry Line

 **0800 882200**

 **www.direct.gov.uk**

Financial and legal arrangements

Although it is relatively easy in the beginning for a carer, or the person with dementia to pay bills, collect the pension, pay the rent and see to other financial affairs, it is best to formalise these arrangements early on to allow a carer to take over these responsibilities in the future.

This is because as dementia progresses the person will be less able to make decisions about their financial and legal affairs. Although some arrangements can be informal there are a number of measures and procedures that are useful.

Mental capacity

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

The act covers decisions relating to an individual's property and financial affairs, together with decisions regarding healthcare treatment and more everyday decisions, such as personal care.

The Mental Capacity Act has particular relevance for people with dementia. In the past it was easy to make decisions for someone instead of allowing them to do it for themselves, because it was assumed they lacked the mental capacity to understand. The Act reverses that assumption and asks people to assume that a person with dementia does have capacity unless otherwise proven.

The Act offers further protection by stating that assessments must be carried out for each separate set of circumstances or decisions, as an individual's ability to

understand may fluctuate depending on the type of decision, time and circumstance.

The Office of the Public Guardian

The Office of the Public Guardian supports and promotes decision making for people who, because of illness, disability or mental health problems, may lack the capacity to make certain decisions for themselves. Operating within the framework of the Mental Capacity Act 2005 it deals with issues relating to an individual's property and financial affairs, healthcare treatment and everyday decisions, such as personal care.

The Office maintains a panel of approved Deputies who can act in cases where nobody else is willing or able to do so; and it manages a register of Lasting Powers of Attorney. It also publishes a number of helpful forms and booklets.

 0300 456 0300

Lasting Power of Attorney (LPA)

A Lasting Power of Attorney (LPA) is a legal document by which you can give someone you trust (your Attorney) the power to act on your behalf, and in your name. It can be drawn up at any time while you have the capacity, but it has no legal standing until it is registered with the Office of the Public Guardian.

The person with dementia should consider making a Lasting Power of Attorney while they still have capacity. It will enable them to appoint one or more people to manage their affairs in their best interests when they are no longer capable.

There are two different types of LPAs:

- A property and financial affairs LPA makes decisions about finances, such as selling

the Donor's house or managing their bank account;

- A health and welfare LPA makes decisions about both health and personal welfare, such as where to live, day-to-day care or having medical treatment.

Powers created can be general allowing full control of affairs, or more specific allowing certain activities such as signing cheques and withdrawing money from accounts.

Court of Protection

If a person has income or savings and there's no one who can take on a Lasting Power of Attorney, it is advisable to apply to the Court of Protection. This will ensure that whoever acts on behalf of the person with dementia does so with legal authority.

The Court of Protection makes decisions in relation to the property and affairs, healthcare and personal welfare of adults who lack capacity. An application may be made to the Court of Protection on behalf of someone who lacks capacity to:

- make decisions on financial or welfare matters
- appoint deputies to make decisions for people
- decide whether a Lasting Power of Attorney is valid
- remove deputies or attorneys who fail to carry out their duties.

Independent Mental Capacity Advocates (IMCA)

An IMCA is someone appointed to support and represent a person who lacks capacity to understand and make decisions about serious medical treatment and long term care moves. The lack of capacity may be due to a dementia, a brain injury, a learning disability or mental health needs. An IMCA

is required if there are no friends or family who can speak on behalf of the person, or if the person has no one with Lasting Power of Attorney, nor a Deputy appointed by the Court of Protection with a power to make decisions in relation to the matter in question.

An IMCA must also be instructed in other circumstances such as when there are allegations of abuse or neglect, if there are Deprivation of Liberty factors, or if there are changes to accommodation that significantly affect the person's quality of life.

The IMCA service is provided by Independent Mental Capacity Advocate Service, Cambridge House.

Deprivation Of Liberties Safeguards (DOLS)

 0207 641 5630

Safeguarding Adults Service Manager

 0207 641 4196

 safeguardingadults@westminster.gov.uk

Advanced Directives

An Advance Directive (also known as a living will) allows someone to specify particular types of treatment they may or may not want in the future. This is important for people with dementia to think about in case they later lack the mental capacity to make these decisions. This may include refusal of life-sustaining treatment. Advance Directives are legally binding and, as long as they meet certain conditions, they must be followed by health professionals. In an Advanced Directive a person may also state that they would prefer to die at home instead of hospital.

Wills

The person with dementia should look at their will and make sure it still expresses their wishes. People with dementia may still have what is known as testamentary capacity – the legal capacity to make or change a will. The solicitor will make a decision about this often after taking medical advice. Age UK Westminster provides a will writing service. See page 12.

Advocacy services

Advocacy services enable people to stand up for their rights to obtain the healthcare, social and housing services they need and want, or make a complaint when services are inadequate. Westminster's Advocacy Plus service offers trained advocates to help senior residents. You can read about the service in more detail on page 35.

Other legal matters

Visit www.lawsociety.org.uk to find details of a suitable local solicitor. Some solicitors may have funding schemes to help with the cost. Remember to check in advance what fees will apply.

Visit www.westminster.gov.uk for more information.

Key Contacts



The Dementia Adviser Service – 0370 192 4265

Older People's Community Mental Health Team	0845 257 9406	Young Onset Dementia Service	020 8206 7110 020 8206 7116
Westminster Memory Service	020 7612 1663	Admiral Nurses	020 8206 7133
Benefits Enquiry Line	0800 882200	Advocacy Plus	020 7439 3131
Citizen's Advice Bureau	0844 477 1611	Alzheimer's Society	0845 300 0336
		Carers Network	020 8960 3033



Section 2: Living well

2.1 Health

General health and dementia

Once diagnosed with dementia it is important that people keep themselves as healthy and independent as possible, for as long as possible. This section of our guide looks at some of the things which help people manage their symptoms. It also explains some of the practical help which Westminster can provide.

The Dementia Adviser Service can provide more information and discuss any concerns.

Visiting your doctor

Having dementia does not mean that a person should feel ill. But people with dementia, especially in later stages, are not always able to say when they are unwell, so it is important to recognise signs of ill-health and check with their doctor.

If a person's behaviour becomes unusual it may be a sign that they are unwell. For example, a sudden onset of increased confusion might indicate a chest or urinary infection; and unusual behaviour such as agitation and restlessness might indicate pain, or constipation.

Regular check ups

Poor vision or hearing, or painful teeth, gums or dentures can make it more difficult for someone with dementia to cope with everyday life. So it is important to have regular sight, hearing and dental checks. Some services offer home visits for people who cannot get out. The Dementia Adviser can give you details of what is available.

The importance of diet

A well-balanced diet is vital for health and wellbeing. Eating plenty of fruit and vegetables, including tinned and frozen foods, helps energy levels and boosts the immune system. People should also drink plenty of fresh water, especially in warm weather, because being dehydrated can cause dizziness and confusion.

People with vascular dementia may be able to reduce the risks of further strokes through diet and exercise. And, of course, diet and exercise can also help prevent depression.

The Westminster Health Trainers can help you review and plan your dietary needs by providing free practical one to one support.

For more information contact

 020 8964 2727

Community health services

The NHS offers a range of services in Westminster, some of them specifically for people with dementia or other cognitive problems. You can access most of these through your GP, who will refer you to the appropriate service.

General Practitioner (GP)

GP's have overall responsibility for a person's health care. As well as being able to diagnose and treat individual illnesses a person's GP will also maintain an overview of their condition to ensure continuity of care as their needs change. GP's are also able to organise services from other professionals in the community, as well as from hospitals.

District Nurses

District Nurses provide care and support to people in their own homes. They work closely with GP's, social care services, hospitals, community matrons, continuing care nurses and voluntary agencies. The service helps people to manage their own medicines safely at home, and can also advise on things like bathing and continence.


Older People's Community Mental Health Teams (CMHT)

Two of Westminster's Community Mental Health Teams provide specialist ongoing assessment and support to people over 65. The teams have several types of workers with different knowledge and skills. Staff work closely together to offer support, encouragement and practical help to their clients, and each client is assigned a key worker to be their main point of contact.

Intermediate Mental Health and Physical Care Team (IMPS)


IMPS provides physical rehabilitation and mental health support to people with dementia who may be recovering from an illness or an accident. The aim is to help them maintain their independence in a safe environment.


The team comprises a number of specialists, including physiotherapists, mental health nurses, psychologists and occupational therapists. People may be referred to the team by their GP, social services, or hospital based teams or specialists.

 **020 8206 7268**
(between 8.00am and 4.00pm)

Westminster Rehabilitation Service (WRS)

The Westminster Rehabilitation Service is similar to the IMPS team and sees people in their own homes, residential homes or other community settings to promote safety and independence in daily living. The team provides a number of services, including Norton House Rehabilitation Unit which offers short periods of rehabilitation in a safe residential environment and Westminster's Falls Prevention Service (see pages 26-27).

 **The Duty Service (for all enquiries)**
020 7641 4001 (Monday to Friday
between 8.30am and 4.30pm)

 **WRS North Team 0207 641 6627**
WRS South Team 0207 641 3960

Hospitals

There is a choice of hospitals available to GPs in Westminster, and it is not necessarily restricted to those that lie inside Westminster's boundaries. Hospitals include:

- Chelsea and Westminster
- University College
- St. Mary's
- Hammersmith
- St. Thomas'
- The Royal Free
- Charing Cross
- Western Eye

Contact details of all the hospitals are listed on page 44.

Admission into hospital

It is sensible for someone with dementia to be prepared in case they need to be admitted to hospital for planned or emergency treatment. Hospitals are responding to the National Dementia Strategy to ensure the needs of patients with dementia are considered, and this includes patients having treatment plans that take into account their individual needs, such as communication, hydration and pain relief.

The Alzheimer's Society has produced a simple and practical tool for people to give to hospital staff to help them understand their condition. Called 'This is me', it is a simple information sheet which tells staff about the person as an individual – their needs, preferences, likes, dislikes and interests.

Charing Cross and St. Mary's hospitals use a similar system, called 'My hospital passport'. The Patient Advice and Liaison Service (PALS) in every hospital exists to provide help, information and advice to patients, their families, carers and visitors.

Being discharged from hospital

After a stay in hospital, the hospital services will work with Westminster Adult Services to make sure plans are put in place for people who are discharged. This may include rehabilitation, or home care services.

2.2 Wellbeing

If you have dementia it is important to be able to relax, unwind and express yourself in creative ways. Westminster runs different types of classes and activities for older people, and some of them are free or offered at a discounted rate. The Dementia Adviser Service can give you more information.

Sporting activities

Although some sporting activities may be more difficult as the illness progresses, it is important to stay fit and healthy and take regular exercise. Walking, swimming, yoga, tai chi and other forms of gentle exercise are great for mind and body and help people maintain social links with the community. There are a number of sports centres across Westminster that offer discounted or free leisure activities for older people. Visit your local leisure centre to find out more.

Housework

Everyone likes to be able to take care of themselves without someone else taking over. Doing housework is a way of maintaining this independence. Washing up, folding clothes, putting away cutlery, sweeping, vacuuming, dusting are all tasks that can still be done. It doesn't matter if things take longer or aren't done perfectly, the importance is in the activity.

Music

Music is a great mood enhancer and it is well known that people with dementia, who may find it difficult to communicate, can still recall all the words of songs from their youth. With modern technology it is possible to have all of your favourite music in an easily accessible format. Technology companies are developing specially designed music systems for people with dementia.

Singing and dancing are also of enormous value because they are great exercise, and stimulate both mood and mind.

Relationships and intimacy

Living with a partner who has dementia is likely to change the nature of the relationship over time. Whilst there may be much love shared, dementia may cause unusual or new behaviours, which can cause a level of frustration, anxiety and/or confusion for the other person in the relationship. People can prepare for these eventualities by getting advice from professionals on how to deal with any changes, and by keeping an open mind. Having a good support network will also be helpful.

Arts in dementia care

It is becoming increasingly recognised that activity in the arts has a major therapeutic benefit in helping to maintain the physical and mental wellbeing of people with dementia. Westminster Arts runs a programme called Resonate that brings the Arts to people with dementia or mental health issues. This includes taking the Arts to people's homes for those who find it difficult to get out.

A number of art galleries, such as the Wallace Collection and the Royal Academy of Arts, run adapted tours for people with dementia. Other organisations offer art classes and arts and crafts sessions, which are usually held in community centres. Many are free, or offered at a discounted rate. These include:

- The Positive Age Centre in W1 offers sessions on drawing, painting & art appreciation/history. Sessions are facilitated by experienced tutors at a low cost.

 **0208 960 4853**

- 60 Penfold Street in NW8 offers sessions on arts & crafts.

 **0208 762 3082**

- Open Age Hub in Glastonbury House offers arts and craft sessions.

 **0207 976 6354**

- Visual Art Course, Club 60 W1T is run by Westminster Adult Education Service.

 **0207 641 7099**

The Dementia Adviser can provide information on current availability and other current events.

Cognitive strategies and memory joggers

Having dementia does not prevent people from engaging in activities that challenge the brain! Completing crosswords or word searches can be fun, and mental exercises can be a great way to keep the brain active and help remember key skills.

Other useful memory joggers can be things like:

- putting labels on cupboards and drawers as a reminder of where things are
- keeping helpful telephone numbers by the phone
- putting important things like keys and glasses in an obvious place
- keeping a notebook to write down important things.

An occupational therapist, together with other skilled therapists, can also help people develop valuable practical steps and routines to take at home which will make it easier to remember the activities of daily living.

Education and libraries

Keeping mentally active is just as important as remaining physically active for people with dementia, and there is no reason why they should not use their local library and education facilities. Westminster's libraries offer a wide range of free talks and events, as well as several readers' groups.

Westminster also offers a Home Library Service for people who are unable to visit a library or carry books home. There are also audio books available on tape or CD. More is available from local libraries or our Library Services team.

 **General Enquiries**
020 7641 1300

Computers

Computers and information technology can help people keep in touch with family and friends, as well as the world in general. They can also provide games and activities that are mentally stimulating; and there are websites specifically for people with dementia that have chat rooms and give advice on living with dementia.

Westminster's libraries provide free access to computers and run free Senior Online (SOL) courses to teach people aged 65+ how to use a computer and the internet. Some of Westminster's specialist day centres also run computer based activities. To find out more, visit the local library.

Cultural and religious needs

Like all of London, Westminster is a diverse borough catering for the cultural and religious needs of many people. There are a number of different groups and services available depending on individual preferences, local libraries can provide more information.

Jewish Care is a charity that provides care and support across London and the South East and provides specialist services to Jewish people with dementia. These services include social work and advocacy, care homes, day centres and a family support service.

 **helpline: Jewish Care Direct**
0208 922 2222

 www.jewishcare.org

Choosing what to do

There are many activities and courses available in Westminster. For more information and advice, contact the Dementia Adviser Service, or call Westminster Adult Education Service, Senior Passport line, your community or adult education college, the Open University or U3A (University of the Third Age).

See pages 41-42 for a list of organisations and their contact details.

2.3 Maintaining independence

Staying safe

Safety on the street

Many people with dementia feel compelled to walk about or leave their homes, which can be worrying for those around them. But although being out and about can present some risks it is reassuring to know that most people with dementia retain their road sense and are rarely involved in traffic accidents. Some walking technologies (sometimes known as tagging) may be able to help. Wearing a device which uses a Global Positioning System (GPS) means people can walk and exercise freely, knowing that they will be easily found if they get lost. Any person wearing such a device must of course give their consent.

The Dementia Adviser Service can help find solutions that will keep people safe without losing their independence or dignity.

Safety at home

Some older people are unsteady on their feet and so are more likely to fall. This can be dangerous, especially for those living alone. Check for anything at home that might cause a fall, such as rugs, loose carpets (especially on the stairs) and slippery floors. Remove trailing flexes, unsteady furniture and clutter or objects lying on the floor.

Preventing falls

Westminster's Falls Prevention Service can assess your home and help you to make it safer. The team can also provide you with information and a programme of exercise to help you reduce the risk of falling.

Individuals can access the service Monday to Friday, 9:00am-4:30pm

 **020 7641 4001**



Assistive technology and Telecare service

'Assistive technology' is a broad term which is used to describe devices or systems that make it easier for a person to perform a task that they would otherwise have difficulty doing, or be unable to do.

Examples of Assistive Technology include automatic pill dispensers, and bed sensors that provide an alert if someone has got out of bed. Although some items can be bought over the counter from the Disabled Living Foundation, others require an assessment.

The Telecare Service provides a home safety and personal security system to help an individual live independently in their own home. It provides cover throughout the night and at weekends when other forms of care are not available. The only requirements are a telephone line and an electrical power

point within six feet of each other. Telecare devices automatically alert the monitoring centre where an operator can organise assistance. Even if someone is unconscious or ill, the call handler will have details of their location and the triggering device. The service is available for vulnerable adults who would like to feel safer in their own home.

The Dementia Adviser Service will be able to tell you if there are items available that can help you.



Getting out and about

For people with dementia it is important to try and maintain their social skills by getting out and about.

Keeping a social life

Even though people may need support from a friend or carer in social gatherings, there is no reason not to go out for a meal, or a coffee, or to the pub if these are activities they enjoy. If someone is worried about it, they can always have a quiet word with the manager or staff before visiting so they can help smooth the way.

People with dementia should try to build up other social activities such as attending a Day Centre, or joining a club, to keep their social life going. It is also helpful to explain their situation to friends and neighbours so they understand, and encourage them to visit for a chat.

See pages 24-25 for ideas about new social activities you might enjoy.

Travel information

Westminster provides a number of transport services to help older people and people with mobility problems travel around more easily. The Taxi Card scheme offers travel by taxi at a reduced rate for a limited number of journeys each year. And the Dial a Ride service provides door-to-door transport for people who find it difficult to use ordinary bus services.

You will need to complete registration forms to assess your suitability for these services. Alternatively, contact Age UK to see if you are eligible to use their voluntary driver's scheme.

Holidays and travel

Being diagnosed with dementia does not mean people cannot go on holiday! Taking breaks and getting away to explore new locations is an important part of maintaining a good quality of life.

Vitalise Essential Breaks is one charity that specialises in providing short breaks and holidays for people with dementia and their carers, and there are others too. Holidays can be tailored to suit individuals needs and are usually available throughout the year.

Vitalise contact number

 **0845 345 1970**



Key Contacts



The Dementia Adviser Service – 0370 192 4265

Intermediate Mental & Physical Care Team 020 8206 7268

Falls Prevention Service 020 7641 4001

Westminster Rehabilitation Service 020 7641 4001

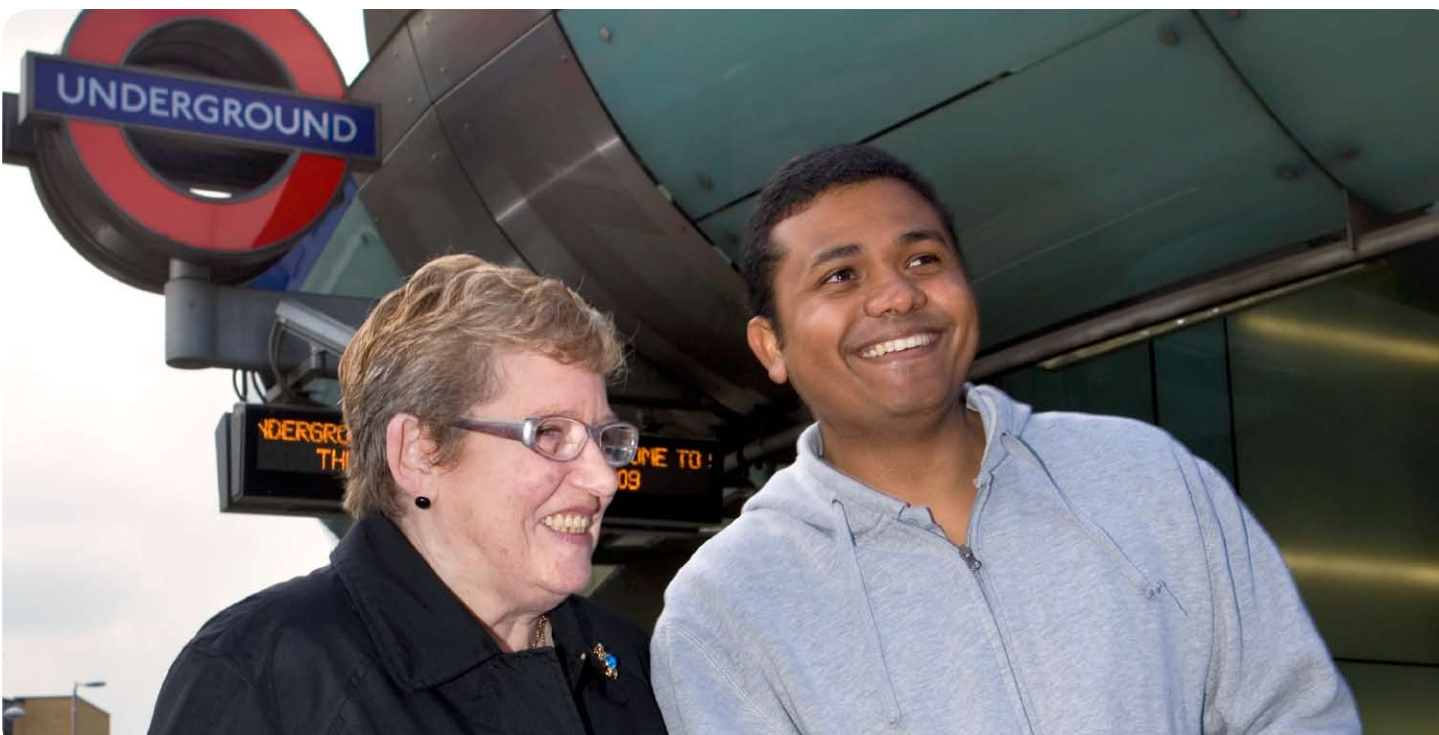
Jewish Care 020 8922 2222

Positive Age Centre 020 8960 4853

60 Penfold Street 020 8762 3082

Open Age Hub 020 7976 6354

Visual Arts Course 020 7641 7099



Section 3: Care services and support networks

3.1 Westminster adult services

Westminster City Council works in partnership with NHS Westminster to jointly plan the health and social care services that residents need. The Adult Social Services Department arranges services and support for people with dementia who live in Westminster, and their family and carers.

The Council wants to give people more choice and control over their lives, which has led to a number of changes in the way Westminster runs its services. Personalisation is a new way of providing social care services and includes:

- Self-assessments
- Helping people to maintain their independence (Re-ablement)
- Providing personal budgets to people who are eligible for Council funding.

Assessing needs

People in the early stages of dementia usually want to remain independent and live in their own home for as long as possible – and Westminster Council will try to support this.

If someone is finding it difficult to cope with some daily activities we can arrange an assessment of their situation to decide what sort of help would best suit their needs. The person will be asked to complete a questionnaire (Supported Self Assessment Questionnaire) with the help of someone from Adult Social Services and this will tell us about their living situation, and how they are currently managing.

Help and support will be delivered through Westminster Council's Adults Services or the person's local GP and Primary Care team. There is a charge for some services depending on individual financial circumstances.

Carer's assessment

Carers over the age of 16 are entitled to an assessment of their own needs if they provide, or intend to provide, a substantial amount of care on a regular basis to help a friend, neighbour or relative with dementia remain living at home.

Direct Payments and Personal Budgets

If a person is eligible to receive services from Westminster City Council's Adult Services Department, they can be given the money to arrange their own care and support through Direct Payments and Personal Budgets. This puts them in control of the services they need, and allows them to choose whom they want to provide that support.

For example, they could choose to employ a personal assistant instead of having a carer provided by the Council, or purchase care from a care agency of their choice. Or they might choose to use some of their personal budget for a specific purpose, such as leisure or community activities. We are happy to help people manage these arrangements if they choose.

Safeguarding adults

One of Westminster Council's aims is to ensure the safety of its residents, and this includes what are termed vulnerable adults. The term 'safeguarding adults' means a range of activities aimed at upholding a vulnerable adult's right to be safe from harm or exploitation – anything from physical or emotional abuse, through to financial exploitation or discrimination.

The City of Westminster Safeguarding Adults Board oversees the safeguarding strategy and its effectiveness. There are a range of

measures to help service users, families, friends, care staff and professionals report and deal with allegations of abuse, as well as a helpline which operates Monday-Friday from 9.00am to 5.00pm.



Helpline: 020 7641 2176



Out of hours call the Emergency Duty Social Services Team: 020 7641 6000



For allegations of crime call the Police operator: 020 7486 1212



www.acwestminster.org.uk



safeguardingadults@westminster.gov.uk

3.2 Community support services

Home care

There are a number of home care agencies which can provide help with things like getting up, washing dressing, preparing meals etc. Home care workers may also help with cleaning, and shopping. The frequency and duration of home care visits will depend on the assessment carried out by Adult Services. In Westminster there is also a specialist home care service for people with dementia. The service can provide workers who will take people out on visits, re-establish old routines, enable people to get to appointments and social events, help manage home affairs and provide personal care.

For more information contact the Dementia Adviser:

 **0370 192 4265**

Re-ablement services

Sometimes an illness or crisis can affect people's independence and confidence in carrying out every day activities. Westminster's re-ablement service provides planned, short-term intensive services to offer practical information and help to find new ways of doing things so people can regain skills and confidence. Re-ablement is free and usually lasts 6 weeks. It is available for residents of Westminster aged 18 or over.

 **020 7641 6278**

 **Text Box : 020 7641 8222**

Day care

Various specialist day centres in Westminster provide services for older people with dementia. Each accommodates about 15 people each day, and they provide daily therapeutic activities, meals and their own transport.

Activities at the centres are designed to help people improve or maintain their cognitive skills and develop their independence. They include things such as music, gardening, exercise and art groups.

Referral to these centres will usually be through a health or social care professional.

There are also other day centres in Westminster for older people. Although they do not provide a specialist service for people with dementia, nevertheless, if someone starts to experience dementia they will continue to support them and include them in the life of the centre for as long as they can. Some of these centres have dementia groups running on particular days of the week.

Day Care: For more information about availability and attending a day centre contact the Dementia Adviser on:

 **0370 192 4265**

Respite services

If you are a carer, or are being cared for by another person, respite care offers the chance of a short break.

- In the person's home. This means someone coming in to take over care in the home for a limited period. It can be for a variety of reasons:
 - so someone can get a good night's sleep once a week
 - help with the caring tasks
 - having someone stay at home with the person with dementia so that the carer can go shopping, or see friends, or go to work
 - taking the person out so the carer can have time at home on their own.
- A short stay in a care home. This gives an extended break for the carer, as the person with dementia will usually stay in one of Westminster's care homes. Carlton Dene has a specialist respite unit for people with dementia.

There is a specialist home based respite service for people with dementia. Westminster Carers Service is a charity that provides home respite for a range of client groups including people with dementia.

For more information contact the Dementia Adviser.

Respite Services: General Enquiries

 **020 7641 1175**

Dementia Adviser

 **0370 192 4265**

Befriending services

Befriending services offer someone with dementia social contact, stimulation and support. Befriending services are especially useful for people who are housebound or live alone, or have limited family contact. A befriender may help with shopping or simple cleaning, or visit someone at home. Age UK Westminster is an example of an agency that provides a befriending service.

Age Uk Westminster

 **020 7724 6930**

3.3 Support services for carers

Caring for someone with dementia can cause strain, and the physical demands of caring can be difficult, whatever the carers age. Caring for someone with dementia can affect the carers health, family life, leisure, employment and finances.

If you are caring for someone and suspect they are having memory problems it is important to seek advice as soon as possible. This is because it could take a while to assess their situation and arrange the support they need.

Help and information

There are a range of services to help people who are caring for someone with dementia, including Carers Network Westminster (see page 12), Age UK (see page 12), Admiral Nurses (see page 12) and Advocacy Plus (see page 35). There are also local and national support services available as well, such as peer support networks, telephone support, and home support visits. The Dementia Adviser Service can provide more information.

Therapeutic support services

Sometimes other forms of support such as family therapy or counselling can be helpful. These services can help individuals or family groups work through their difficulties and develop solutions that meet the needs of everyone concerned. Westminster City Council can often offer counselling and family therapy services (after referral and assessment).

Therapeutic Support Services:
Westminster City Council

 **020 7641 1444**

Six Steps Forward seminars

This is a series of free, informal talks for carers, relatives and supporters of people with dementia. These seminars cover a wide range of themes and are designed to be interesting as well as useful. Sessions run once every two months and include a free buffet lunch. Six steps forward is run by the Dementia Adviser Service.

Support groups

There are a number of support groups in and around the borough of Westminster that offer ongoing peer support to carers, including those who care for people with dementia. As well as traditional group meetings there are internet forums and networks. The Dementia Adviser Service can provide more information.

Respite services

It is important for family carers of people with dementia to have occasional breaks. Help can be provided in the home for a limited period – perhaps having someone to stay while your carer goes shopping, or visits friends, or maybe helping with some caring tasks. Alternatively, respite care can be offered as a short stay in a care home to provide an extended break.

Advocacy Plus

Some people find it difficult to stand up for their rights and have their voice heard. People with dementia, in particular, may be unable to clearly express their needs. Westminster wants its senior residents to be able to take decisions about their own lives and to support the choices they make.

Advocacy Plus services provide specialist advocates for senior residents of Westminster. They are experienced in helping people with dementia and will listen to their views and wishes, provide information, and discuss options. They will also help people in their dealings with service providers to help them obtain the healthcare, social and housing services they need, or to make a complaint if services are inadequate.

Advocacy Plus provides trained volunteer advocates to enable all older people in Westminster to express choices about matters affecting their everyday lives and so achieve a better quality of life. They also have workers who specialise in the following:

- **Dementia Advocacy**

Advocacy plus provides a service for people with dementia and has a team of specialist dementia advocacy workers.

- **Independent Mental Health Advocate (IMHA)**

An Independent Mental Health Advocate is available to support people who may be detained under the Mental Health Act, or subject to treatment orders. The IMHA role is to make sure the patient's voice is heard, support patients to access information, and to better understand the options available to them.

- **Housing Advocacy Worker**

A Housing Advocacy Worker is available to help with the big decisions about moving into more appropriate housing such as sheltered housing, or transfer into a residential home. Or the issue may be claiming the right housing benefits, problems with a landlord or getting repairs or adaptations done.

- **Hard to reach groups**

Advocacy Plus policy is to reach out to a whole range of people who for different reasons find it difficult to access services. It is part of the work of all advocates to make contact with people who are more isolated in the Westminster community.

Advocacy Plus can be contacted at 55 Dean Street London W1D 6AF

 **on 020 7439 3131**
Fax:020 7297 9385

 **Minicom telephone on 020 7434 2083**

 **info@wassr.org**

3.4 Housing and longer term care

Care options

Dementia is a progressive illness, which means people often eventually need more help to manage daily life. Westminster is committed to helping its older residents live as independently as possible, for as long as possible. But when longer term care is needed there are a number of options to consider.

Extra care housing

Extra care housing is a step up from what used to be known as sheltered housing and is often seen as an alternative to residential care. Extra care housing schemes allow people who need daily support to remain independent and live in their own self-contained flat, with care staff on hand to help if needed. New schemes are purpose built and usually offer flats with a kitchen, living area, and separate bedroom and bathroom. Often assistive technology is wired into the fabric of the building.

Westminster has two extra care facilities and is looking to develop more. 60 Penfold Street is an example of a purpose built extra care scheme run by Nottingham Housing. The buildings are designed around a central garden and include 43 extra care sheltered flats and two four bed units for residents with dementia. On the ground floor is a resource centre with medical treatment, chiropody and therapy rooms.

Care Homes

If it is difficult to manage independently at home due to problems such as physical frailty or a dementia, it can be worthwhile considering a move into a care home. There are two main types of care home. Some offer

accommodation and help with personal care, such as washing, dressing and going to the toilet. Others provide those services and also offer nursing care. Until recently these two types of care home were classified as 'residential homes' and 'nursing homes'. There are also care homes for those who require extra care and support, often due to dementia.

There are a number of residential care options in Westminster run by the Council and other, independent, providers. Some have a mix of nursing and care, while others just provide care. Some also cater for people with dementia. Forester Court, in particular, has a Young Onset Dementia Unit, which is for people under the age of 65. The Senior Passport Line and the Dementia Adviser will be able to provide up-to-date information on what is available.

Choosing a residential home

The kind of care that someone with dementia receives in a residential home can make a big difference to their behaviour and quality of life. The Alzheimer's Society has information sheets on choosing long term care.

Arrangements for care may be made through the City of Westminster, or independently. Either way, it is a good idea for people to visit a number of homes before making a final choice, and to be sure they spend enough time at the home to get a good idea of what it is like. For those looking for a residential home for someone with dementia it is advisable to visit on several occasions, both with and without the person, to gauge their reactions and see how they might settle in. Recent inspection reports for the home will provide a lot of detail on how it operates



before making a final decision. The home should be able to provide a copy of the latest inspection report, or they are freely available on the Care Quality Commission (CQC) website.

A trial period is usually recommended and this can be discussed with the home's manager.

Continuing healthcare

NHS continuing healthcare is the name given to a package of care which is arranged and funded solely by the NHS for individuals outside of hospital who have ongoing health care needs. A person can receive continuing healthcare in any setting, including their own home or a care home. The service is free, unlike help from social services for which a financial charge may be made depending on the individual's income and savings.

In a person's own home, this means the NHS will pay for healthcare (e.g. services from a

community nurse or specialist therapist) and personal care (e.g. help with bathing, dressing and laundry). In a care home, the NHS also pays for the care home fees, including board and accommodation.

The Butterworth Centre, which is part of the hospital of St. John and Elizabeth, provides continuing care for Westminster residents with mental health problems who require specialist care.

To be eligible, people are likely to have a complex medical condition that requires a lot of care and highly specialised nursing support; and they will have to have a full assessment of needs for funding to be considered.

NHS-funded nursing care

If you do not qualify for NHS continuing healthcare, but you do need to receive some nursing care, then that care can be provided in a care home by a registered nurse. The home will have to be registered to provide nursing care.

Although the NHS is responsible for arranging and funding this nursing care, all other aspects of the care have to be funded separately. Means testing is used to decide what proportion of the care will be paid for by Westminster Council, and what proportion by the individual.

Palliative care

The goal of palliative care is to prevent and relieve suffering, and to improve the quality of life for people facing a serious, complex illness. Palliative care and hospice services are available in Westminster to everyone who needs them.

Hospice care in Westminster is provided at St. John's Hospice. This type of care is also available at the Pembridge Palliative Care Centre in Kensington & Chelsea and Trinity Hospice in Clapham. St John's Hospice also has a community team that provides a hospice at home service.

People with advanced dementia have additional needs and a specialist dementia palliative care nurse – the Dementia Voice Nurse – is available to help identify and coordinate the care that is needed. The nurse also works with families, home care staff and other health and social care professionals. The Dementia Voice Nurse works closely with the palliative care teams at St John's Hospice.

If you have an Advance Directive, or living will (see page 17), you may already have specified how you want to receive care and treatment in the future. Your directive may be held by a family member or your care manager and its contents will be shared amongst the people looking after you so your wishes can be carried out.



Key Contacts



The Dementia Adviser Service – 0370 192 4265

Westminster Adult
Dementia Services

020 7641 6000

Advocacy Plus

020 7439 3131

Dementia Voice Nurse

020 7641 7694

Safeguarding Adults

020 7641 2176

Care Quality Commission

0300 616161

Essential reference and directory

A who's who of help

Social Worker – Care Manager

Social workers can assess the need for care and arrange for suitable services. They can advise on practical matters such as finances, day care, accommodation and local services. They can help sort out problems with care packages or if a person is in hospital, and help to arrange services for when someone is discharged.

Occupational therapist

They advise people on ways of maintaining skills and independence for as long as possible. They can provide information about aids and adaptations within the persons home.

Consultant

Consultants are qualified doctors who have further extensive training in a particular speciality. This may be in neurology geriatrics or psychiatry.

Psychiatrist

A medical doctor specialising in mental illness for any age group.

Old age psychiatrist

A specialist in mental illness, including dementia among older people. People may be referred to a psychiatrist to assist in diagnosis and for advice in dealing with the illness.

Neurologist

A specialist in diseases of the brain and nervous system.

Clinical psychologists

Clinical psychologists offer a range of therapeutic approaches to help people cope with mental and behavioural difficulties they are experiencing in their lives.

Community mental health nurse (CMHN)

These are qualified nurses who support people with mental health problems and their families in the community. They can carry out assessments of people in their own homes and advise on ways to deal with behavioural problems.

Admiral Nurses

A specialist community practise nurse with experience in working with people with dementia.

District nurse

A district nurse is a nurse who provides nursing care at home. They can visit on a regular basis to help with more complicated care such as wound care and to change dressings.

Continence adviser

Continence adviser offers advice about the management of incontinence.

Palliative care nurse

A specialist nurse who provides care to terminally ill people.

Dementia Voice Nurse

A speciallist nurse who co-ordinates palliative care for people with dementia.

Support services and agencies



General numbers

Westminster City Council	020 7641 6000	
Senior Passport line	020 7641 1444	
Westminster Adult Services	020 7641 6000	(after hours emergencies)
WELDIS	020 7641 1444	
Housing Assessment and Advice	020 7641 1000	



Leisure and outings

The Positive Age Centre		
Peabody Estate, W1	020 8960 4853	
60 Penfold Street, Church Street, NW8	020 8762 3082	
Westminster Public Libraries	020 7641 1300	
Home Library Service	020 7641 5405	
Westminster Adult Education Service (WAES)	020 7641 5405	
Open Age Hub, Glastonbury House, SW1V 4NT,	020 7976 6354	
Open Age	020 8964 1900	
Age UK Reaching U	020 3004 5610	
A joint project between Age Concern Westminster, Open Age and Westminster Adult Education Service. It offers a programme of weekly learning activities for the over 50s		
Age UK Westminster	020 3370 3030	
Covent Garden Centre (Hub)	020 3370 3030	
E42 Odhams Walk Off Shelton Street London WC2H 9SB		

Leisure and outings continued

Cathay Club for Chinese Elders 020 3370 3030

A club for Chinese elders,
every Monday afternoon.

E42 Odhams Walk
Off Shelton Street
London WC2H 9SB

Specialist day centres

Tresham Day Centre 020 7641 1636

27 Tresham Crescent, NW8 8TW

Carlton Dene Day Centre 020 7641 4890

Carlton Dene Elderly Resource Centre
45 Kilburn Park Road, London NW6 5XD

Blenheim Day Centre 020 7078 3820

Top Floor, Butterworth Centre,
The Hospital of St John and St Elizabeth
36 Circus Road, London, NW8 9SE

Older people's day centres

Pullen Day Centre. 020 7932 0140

(provides one day a week for people with
dementia)

Garden Terrace, 7-9 Moreton Street
London, SW1V 2WP

Elgin Day Centre 020 7286 2043

63 Elgin Avenue, London, W9 2BX

Sherborne Day Centre 0370 192 4976

Sherborne House, Winchester Street
London, SW1P 4LP

 Advice, support, finance and legal

Age UK Westminster 23-25 Praed Street, London, W2 1NJ	020 3004 5610 enquiries@acwestminster.org.uk www.acwestminster.org.uk
National Age UK information line	0800 169 6565
Benefits Enquiry Line	0800 882200 www.direct.gov.uk
Office of the Public Guardian	020 7874 7210 customerservices@publicguardian.gsi.gov.uk www.publicguardian.gov.uk
Admiral Nursing DIRECT	0845 257 9406
Uniting Carers	020 7874 7225 020 7874 7209
Advocacy Plus 55 Dean Street, London, W1D 6AF	020 7439 3131
Dementia Adviser service	0370 192 4265 07540 502 379
Citizens Advice Westminster Paddington office Pimlico office 441 Harrow Road 140 Tachbrook Street London London W10 4RE SW1V 2NE	0844 477 1611 www.citizensadvice.org.uk/westminstercab

 General health

Emergency dental or GP Service helpline	020 7377 7151
NHS Direct	0845 4647
NHS Westminster	020 7150 8000
Patients Advice and Liaison Service (PALS)	0800 587 8818
Minicom	020 7486 9582



Walk in health centres and minor injuries

Soho Centre for Health	020 7534 6500
St Charles Hospital – minor injuries	020 8962 4262
Victoria NHS walk-in centre	020 7340 1190



Hospitals

Chelsea and Westminster Hospital 369 Fulham Road London SW10 9NH	020 8746 8000 www.chelwest.nhs.uk
St Mary's Hospital Praed Street London W2 1NY	020 7886 6666 PALS: 020 3312 7777 www.imperial.nhs.uk/stmarys
St Thomas' Hospital Lambeth Palace Road London SE1 9RT	020 7188 7188 www.guysandstthomas.nhs.uk
University College Hospital Grafton Way London WC1E 6AU	0845 1555 000 www.uclh.org
The Royal Free Hospital Pond Street London NW3 2QG	020 7794 0500
Western Eye Hospital 171 Marylebone Road London NW1 5QH	020 7886 6666 PALS: 020 3312 7777
Hospital of St. John & Elizabeth 60 Grove End Road London NW8 9NH	020 7806 4000



Care homes

Carlton Dene Elderly Resource Centre 020 7641 4890

45 Kilburn Park Road
London NW6 5XD

Westmead Elderly Resource Centre 020 7641 4595

4 Tavistock Road
London W11 1BA.

Forester Court 020 7266 3174

5 Cirencester Street
London W2 5SR

Butterworth Centre 020 7078 3830

60 Grove End Road
London NW8 9NH



Death, dying and coping with loss

Camden, Islington Bereavement Service 020 7284 0090

Westminster registrars 020 7641 1162

Cruse Bereavement Care 0844 477 9400

National Association of Funeral directors 0845 230 1343

St John's Hospice 020 7806 4040

Hospital of St. John & Elizabeth
60 Grove End Road
London NW8 9NH

Dementia Voice Nurse 020 7641 7694



Useful websites

www.citizensadvice.org.uk

www.marywardlegal.org.uk

www.publicguardian.gov.uk

www.adviceguide.org.uk

www.cqc.org.uk



City of Westminster



Westminster

Central and North West London 
NHS Foundation Trust



0370 192 4000
www.housing21.co.uk

Housing 21 is an exempt charity