

West London
Clinical Commissioning Group





# Living Well with Dementia

The Royal Borough of Kensington and Chelsea Guide





Adapted from "Living Well With Dementia, the Westminster Guide" published by Housing 21, 2013.

Rewritten and updated for The Royal Borough of Kensington and Chelsea by Age UK Kensington and Chelsea.

To request further copies of this guide, please contact Holly Corlett, Dementia Advisor



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## Introduction

## About this guide

Welcome to the The Royal Borough of Kensington and Chelsea Dementia Guide. It has been written to give an overview of the services and support available in The Royal Borough of Kensington and Chelsea 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 varying ways, and every person's experience of dementia is different.

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.

This guide is hopefully something that you can refer to at different times.

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 The Royal Borough of Kensington and Chelsea, and their different roles and responsibilities. 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.

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

If you are in any doubt, contact the Dementia Advisor on **020 8960 8137** (Monday to Friday 9am-5pm) who will be happy to help.

## Frequently asked questions include:

What is dementia?

How will dementia affect me?

What services are out there to help me?

Is there any support for my family?

What benefits are me or my family entitled to? (See page 10)

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

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

Are there things I can do to help myself?

Will I lose my independence?

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

## 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 The Royal Borough of Kensington and Chelsea, and their different roles and responsibilities. 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..

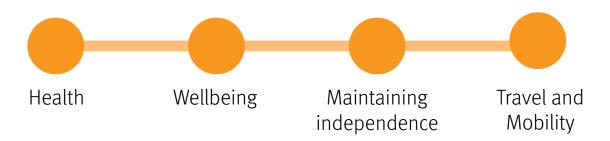
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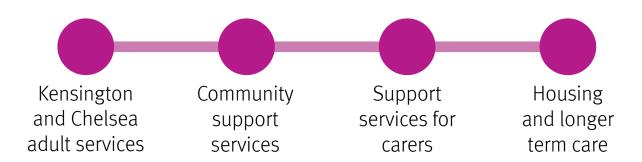
## Section 1: Understanding dementia



## Section 2: Living well



## Section 3: Care services and support networks



## **Section 1: Understanding dementia**

## 1.1 What is dementia?

Dementia is an umbrella 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 or by brain cells wearing out at a faster rate than would be expected in normal ageing.

Dementia is progressive, 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. Areas which may be affected include:

- memory
- mood.
- language
- personality
- judgement
- motivation
- problem solving
- communication

Those with dementia can still have a good quality of life, but may require more help with day to day tasks as time goes on. The rate at which a person's dementia will progress is difficult to predict, and is different for everyone.

#### Facts and figures

Dementia is common - you are not alone, sadly dementia often goes undiagnosed due to poor awareness or understanding of the condition.

It is estimated that over 800,000 people in the United Kingdom have a type of dementia. In The Royal Borough of Kensington and Chelsea we estimate that there are around 1450 people living with dementia. NHS Kensington and Chelsea estimate an increase within the borough to approximately 1500 by 2021.

As people live longer, the number of people with dementia is set to increase. Nationally it is estimated that the numbers may nearly double over 30 years to 1.7 million people living with dementia within the UK.

Dementia affects both men and women. Statistically, more women than men have dementia, but this is possibly because women tend to live, on average, five years longer. The likelihood of developing dementia increases with age, however a small minority of people are diagnosed from their forties onwards

## Types of dementia

#### Alzheimer's disease

This is by far the most common cause of dementia and accounts for 62% of all cases. In Alzheimer's patients, there is a progressive shrinkage in the brain. Protein 'plaques' and 'tangles' also develop, which destroy more brain cells, and there is a shortage of some of the chemicals used to send messages in the brain. Damage is usually 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 (around 17% of all cases) 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 wise'. Whereas Alzheimer's 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 disease and accounts for around 4% 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 dementia, 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 (Creutzfeld Jacob Disease)
- Huntingdon's Disease
- HIV related dementia
- Motor Neuron Disease
- Downs Syndrome
- VCID
- · Korsakoff's.

#### 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.

## 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 that 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, which affects what treatment is appropriate.

Some people feel better once they have an explanation and an understanding of what they have been experiencing.

In The Royal Borough of Kensington and Chelsea, you will most likely have participated in an assessment with the Kensington, Chelsea and Westminster Memory Service.

#### After diagnosis

Following the feedback meeting with your clinician, you will be informed of the next steps that your treatment can take. In some cases, you will be offered medication that may help with your memory problems, and the team may also speak to you about services available in The Royal Borough of

Kensington and Chelsea that can assist you to remain independent at home.

The service also has a responsibility to inform your GP of the outcome and the type of treatment you are receiving. A letter will be sent to your GP detailing this information and if requested, you will also receive a copy of this letter for your future reference.

#### Discharge and ongoing support

Once all treatments and related interventions have been initiated and/ or completed by the service, your case will be closed by the team and you will be discharged back to the care of your GP. If during the process you were started on any medication, the service may monitor this initially before asking your GP to prescribe it.

If you are discharged from the service, this does not mean that you no longer have any access to support or information. Prior to discharging you from the service, you will be provided with lots of support and information on local specialist services that can assist you.

#### Feedback and research

Research projects into dementia take place often. If you are interested in taking part in some research, the Kensington, Chelsea and Westminster Memory Service will be able to provide you with details.

## 1.3 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 help slow down the progression of Alzheimer's and to alleviate some of the symptoms associated with dementia. They are not a cure. They are usually used in the early to moderate stages. These drugs are often referred to as anti-dementia drugs and include:

Donepezil (Aricept)
Galantamine (Reminyl)
Rivastigmine (Exelon)
Ebixa (Memantine).

Donepezil and Galantimine are prescribed for people in the early to moderate stages of dementia.

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

Memantine is a drug which is thought to benefit those in the moderate to severe stages of Alzheimer's dementia.

Whilst these drugs may slow down the progression of Alzheimer's for some people, every person will respond differently and the effects can vary considerably from person to person. Also, not every person will be eligible for medication, and whether they can take it will depend upon a number of factors.

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 alleviate 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 to 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 may find it increasingly difficult to manage. 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, as well as checking to see what benefits they and their family are entitled to.

#### **Driving**

If you receive a diagnosis of dementia and you are still driving, you must inform the DVLA and your insurance company.



**(**) 0300 790 6801



#### 😭 DVLA, Swansea, SA6 7JL.

Having a diagnosis of dementia does not mean you will automatically be banned from driving. The DVLA will most likely contact the person who made your diagnosis to ask about your abilities, and you may be required to attend an assessment centre. 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.

#### 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, 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 complex, and changes so often, so it can get very confusing, but Age UK Kensington & Chelsea and the Citizens Advice Bureau 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.



0800 882200



www.gov.uk/benefit-enquiry-line

#### 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 may find it more difficult 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.

#### 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.



**2** 0300 456 0300



www.direct.gov.uk

- **(a)** customerservices@publicguardian. gsi.gov.uk
- (1) PO Box 16185, Birmingham, B<sub>2</sub> 2WH.

#### **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, should a time come when you are unable to do so. 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.

There are two types of LPAs:

- A property and financial affairs LPA makes decisions about finances, such as selling the person'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 is 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.

#### **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. 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, or 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.

POhWER currently provide an IMCA service in The Royal Borough of Kensington and Chelsea.



0300 456 2370



pohwer@pohwer.net



www.pohwer.net

## Advance Decisions and Advance Statements

Advance Decisions enable you to decide beforehand what medical treatment you would like to refuse and are legally binding. Advance Statements explain how you would like to be cared for including religious beliefs and matters such as food and bathing preferences, but are not legally binding. Both of these can be used should something happen and you are unable to communicate your decisions or lack the capacity to do so. It may be beneficial to discuss this with your GP. A form to help you draft an Advance Decision can be downloaded from



#### Wills

A Will states what you would like to happen to your possessions, including your property and money, after you die and also ensures that unnecessary taxes are not paid. If no Will has been made, the government will be responsible for deciding what happens to your possessions. You can make a Will without assistance, but many people seek legal advice as it can be quite complicated. You will need to select a person/people to act as executor and you should inform someone where your Will is kept. It is recommended that you review your Will approximately every five years and changes can be made by adding a supplement called a codicil which is signed and witnessed in the same way as the original Will.

#### Other legal matters

If you are living on a low income or benefits, you may be eligible for free specialist advice from legal advisers on issues including: benefits and tax credits, debt, education, housing, employment, and family problems.

Community Legal Advice (CLA) is a free and confidential advice service in England and Wales paid for by legal aid.

The advice is independent and confidential. Community Legal Advice will ask you questions about your problem and find out what help you need. You will be asked a number of questions about your finances to see if you are eligible for legal aid. Community Legal Advice also has a free translation service available in 170 languages. If they are unable to help with your query, they will be able to put you in touch with someone who can.

Visit the 'People First' pages on the Royal Borough of Kensington and Chelsea's website at www.rbkc.gov.uk for further information, or make enquiries at your local Citizens Advice Bureau.



www.rbkc.gov.uk

## Key contacts













#### The Dementia Advisor Service - 020 8960 8137

020 3219 0910 Kensington, Chelsea and Westminster Memory Service

Alzheimer's Society 020 7423 3500 enquiries@alzheimers.org.uk www.alzheimers.org.uk

0800 882200 Benefits Enquiry Line www.gov.uk/benefit-enquiry-line

Citizens Advice 0844 826 9708 Kensington and Chelsea

Community Legal Advice 0845 345 4 345 www.direct.gov.uk

DVLA	0300 790 6801
	Swansea SA6 7JL

**POhWER** 0300 456 2370 pohwer@pohwer.net www.pohwer.net

The Office of the 0300 456 0300 Public Guardian customerservices@ publicguardian.gsi.gov.uk www.direct.gov.uk PO Box 16185 Birmingham B2 2WH

People First www.rbkc.gov.uk



## **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 that help people manage their symptoms. It also explains some of the practical help which can be found in Royal Borough of Kensington and Chelsea.

#### **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.

#### **Continence**

Other conditions such as incontinence can also add to a person's difficulties especially if they suffer from dementia. A sudden onset or worsening of incontinence may indicate a urinary or other infection that needs treating. Help is available in managing such problems, so speak to your GP, community nurse or the Continence Promotion Service.

Based at St Charles Centre for Health and Wellbeing, the Continence Promotion Service provides clinical advice and treatment for men and women with bladder and/or bowel dysfunction who live in the Kensington, Chelsea and Westminster areas. They can also provide information for patients' carers as required. The service includes specialist continence nurses and physiotherapists. Referrals are accepted from anyone, including patients who wish to refer themselves. Patients are seen individually by appointment at one of the available clinics.



020 8962 4546



continence.promotionservice@clch.nhs.uk

#### 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 nutrition and dietetics service includes a weight management programme, support for people who have a low BMI (underweight) and six-week Cook and Taste programmes designed for older people.



020 7313 3059



dietitians.kc@nhs.net

Age UK Kensington & Chelsea also provides a Food and Friends service, whereby volunteers visit people at home to share a meal together, providing valuable company over meal time. They also hold regular lunch clubs where people can meet others and enjoy a sociable lunch together, in a variety of community venues.



020 8960 8137



health@aukc.org.uk



www.aukc.org.uk

Health Trainers are also available in The Royal Borough of Kensington and Chelsea. They are members of the local community who have been trained to support people to improve their health and wellbeing. Through free one-to-one sessions, a Health Trainer can work with someone to assess their current lifestyle and help set realistic goals in order to make healthy changes, such as improving diet, increasing exercise or stopping smoking.



020 8962 5730



healthtrainers@westway.org

#### Community health services

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

#### **General Practitioner (GP)**

GPs 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. GPs 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 GPs, 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 such as bathing and continence.

#### **Older People's Community Mental Health Teams (CMHT)**

Royal Borough of Kensington and Chelsea's Older People's Community Mental Health Teams provide specialist ongoing assessment and support to people over 65. Although the work of the CMHT is not exclusive to people with memory difficulties or dementia, the teams have workers with a range of specialist 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.

The CMHT staff work at different venues. including GP surgeries, outpatient clinics, people's own homes and St Charles Centre for Health and Wellbeing in Exmoor Street, W10 6D7.



**2** 020 8206 7148

#### **Kensington and Chelsea Community Rehabilitation Service**

The Kensington and Chelsea Community Rehabilitation Service 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 a Falls Prevention Service, injury prevention advice for informal carers and an inpatient rehabilitation service, which offers short periods of rehabilitation in a safe residential environment aimed at helping prevent hospital admissions.



020 7361 2600



intermediatecare@nhs.net

#### Hospitals

A choice of hospitals is available to GPs in The Royal Borough of Kensington and Chelsea and is not necessarily restricted to those that lie inside the borough's boundaries. Hospitals include:

- Chelsea and Westminster (including Accident and Emergency)
- St. Mary's (including Accident and Emergency)
- Hammersmith
- The Royal Marsden (specialist cancer treatment centre)
- The Royal Brompton
- Charing Cross

An Urgent Care walk-in centre is available at:

St Charles Centre for Health and Wellbeing

Contact details of all the hospitals are listed in the directory pages at the end of this booklet.

#### 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.

The Patient Advice and Liaison Service (PALS) in every hospital provides 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 The Royal Borough of Kensington and Chelsea Adult Social Care 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. There are different types of classes and activities for older people available in The Royal Borough of Kensington and Chelsea, and some of them are free or offered at a discounted rate.

The Dementia Advisor or your local Health Trainers can give you more information.

#### Physical activity and exercise

Although some physical and sporting activities may become more difficult as the illness progresses, it is important to stay fit and healthy and take regular exercise. As well as the benefits to physical health, exercise such as walking, swimming, yoga, tai chi and other forms of gentle exercise have been shown to have positive effects on mood, short-term memory, comprehension, concentration, mobility and general wellbeing. The social aspect of being involved in group exercise is also greatly beneficial, particularly for those who live alone.

Age UK Kensington & Chelsea facilitate an 'Exercise for the Mind' programme, which involves engaging in various forms of gentle exercise, specifically for people who have memory difficulties or dementia. They also provide an Exercise at Home service, whereby volunteers visit people in their own homes to carry out a number of gentle exercises on an individual basis.

**2**0 020 8960 8137

mealth@aukc.org.uk

www www.aukc.org.uk

There are a number of sports centres across The Royal Borough of Kensington and Chelsea that offer discounted leisure activities for older people.

Most centres are fully accessible for people with disabilities. You can also ask your GP or the leisure centre staff about the 'exercise on referral' scheme, where your doctor can refer you for exercise as part of a treatment plan for certain medical conditions.

Outside of the traditional sports and leisure centres, organisations such as Open Age hold physical activity sessions for older people in various community venues.

**2**0 020 8964 1900

mail@openage.org.uk

www www.openage.org.uk

The Second Half Centre at St Charles Centre for Health and Wellbeing in North Kensington also holds a number of exercise classes.

**2**020 8962 55 00

(@) info@thesecondhalfcentre.com

www.thesecondhalfcentre.com

The local Health Trainers scheme can give personal support and advice to help build activity into daily life, as well as making other healthy changes.

020 8962 5730



healthtrainers@westway.org

#### **Walking**

Walking is one of the healthiest things we can all do. The Royal Borough of Kensington and Chelsea Sports Development Team organise low cost or free guided health walks in various locations in the borough



020 7938 8179



sportandleisure@rbkc.gov.uk

#### 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 are not done perfectly – it is the activity that is important.

#### Relationships and intimacy

Living with a partner who has dementia is likely to change the nature of the relationship over time. While there may be much love shared, dementia may result in unusual or new behaviours which can cause a level of frustration, anxiety 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.

#### 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 provide great exercise, and stimulate both mood and mind.

#### Arts in dementia care

It is becoming increasingly recognised that activity in the arts has a major therapeutic benefit, helping to maintain the physical and mental wellbeing of people with dementia.

The creative part of the brain can remain undamaged for years after the onset of dementia and continuing to use our creativity can help to override the stresses of memory loss, elevate mood, re-energise and restore a sense of personal identity.

Arts4Dementia is an organisation that works in partnership with various arts organisations throughout central London to provide tours, workshops, performances and courses on a whole range of artistic subjects for people with memory loss, their families and carers



020 8780 5217



(a) info@arts4dementia.org.uk



www.arts4dementia.org.uk

The Arts Therapists at St Charles Centre for Health and Wellbeing can also provide individual and group drama, art and music therapy.



#### **(2)** 020 8206 7180

The Dementia Team at Age UK Kensington & Chelsea runs creative workshops incorporating music, art, poetry and movement for people with dementia, to help maintain mental stimulation, physical activity and socialisation.



**2**) 020 8960 8137



(a) health@aukc.org.uk



www www.aukc.org.uk

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.

Open Age runs creative activities for people over 50 at a variety of community venues throughout the borough including Art for All at the Positive Age Centre in Dalgarno Way, W10 5JN. Open Age have Link-Up workers who can help isolated people over 50 to discover and decide which activities may suit them best.



020 8964 1900



@) mail@openage.org.uk



www.openage.org.uk

New Horizons in Cadogan Street also run Art for Fun, a drawing group, and art history classes as well as many other creative pursuits.



020 7590 8970



www.new-horizons-chelsea.org.uk

The Second Half Centre based in St Charles Centre for Health and Wellbeing offers a range of art classes such as painting, life drawing, craft, tapestry and more.



0208 962 5500



(a) info@thesecondhalfcentre.com



www www.thesecondhalfcentre.com

#### 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 include:

- 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 use at home which will make it easier to remember the activities of daily living.

Age UK Kensington & Chelsea run Ageing Well and Memory Management sessions designed to help people discuss and learn about various coping strategies for living well with memory problems.

The Dementia Advisor can also help you to adopt strategies which work for you to aid your memory.

#### **Education and libraries**

Keeping mentally active is just as important as keeping physically active for people with dementia, and there is no reason why they should not use local libraries and education facilities. Royal Borough of Kensington and Chelsea's libraries offer free talks and events as well as several readers groups.

A 'Bibliotherapy' service is also operated by The Royal Borough of Kensington and Chelsea libraries. This includes 'Book Breaks' which are reading groups led by a facilitator who reads stories and poems aloud. Participants can read or take part as much or as little as they like, and there are plenty of opportunities to discuss what has just been read. Tea, coffee and biscuits are also provided.

The Royal Borough of Kensington and Chelsea also offers a Home Library Service for people who are unable to visit a library or carry books home. They can visit every four weeks. There are also audio books available on tape or CD for those who find reading difficult.

**2** 020 7361 3010

(@) libraries@rbkc.gov.uk

#### **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.

The Royal Borough of Kensington and Chelsea's libraries provide free access to computers and the internet and a number of their computers have screen reader software installed. This enables people with visual impairments to use a computer to surf the internet or write documents. The software reads the contents of the screen aloud to you.

Open Age runs computer classes at various locations.

**2**0 020 8964 1900

mail@openage.org.uk

www.openage.org.uk

Age UK Kensington & Chelsea also provides a computer project through their intergenerational work. This is aimed at people who cannot go to classes due to frailty or lack of confidence, or those who wish to use their computer at home. The project uses young volunteers as computer coaches for older people. The older person will set their own learning goals, whether learning to use the internet, a digital camera or a mobile phone. They also hold digital clinics for people to get assistance with using their gadgets.

**2**020 8969 9105

(@) information@aukc.org.uk

www www.aukc.org.uk

#### Cultural and religious needs

Like all of London, The Royal Borough of Kensington and Chelsea is a diverse borough catering for the cultural and religious needs of many people. There are a wide number of different cultural groups and services available in the borough.

Age UK Kensington & Chelsea offers a Wayfinder Service designed to help you find local services and access information. They can provide volunteers who speak a wide range of community languages (including Arabic, Amharic, Somali, Spanish and Tigrinya) to help identify and access the services that vou need.

**(2)** 020 8960 9105



information@aukc.org.uk



www.aukc.org.uk

Another source of local information is the Kensington and Chelsea Social Council (KCSC). They are the local Council for Voluntary Service (CVS) and act as an umbrella body for voluntary and community organisations in The Royal Borough of Kensington and Chelsea. They also have a searchable directory of voluntary and community organisations on their website



020 7243 9800



www.kcsc.org.uk

Alternatively, enquire at your local library.

The Persian Care Centre offers an opportunity for Farsi speaking older people in the borough to socialise and get involved in activities and cultural events.



020 7221 5763

The Forum aims to support the integration of migrants and refugees in London.



**(全**) 020 8962 3048



www www.mrcf.org.uk



(a) 2 Thorpe Close, London W10 5XL.

#### Choosing what to do

There are many activities and courses available in The Royal Borough of Kensington and Chelsea. For more information and advice contact the Dementia Advisor, or the Link-Up Worker with Open Age, or your local library or community or adult education college.

#### Key contacts











Age UK	020 8969 9105
Kensington	information@aukc.org.uk
& Chelsea	www.aukc.org.uk

Alzheimer's Society

Arts4Dementia 020 8780 5217

**CNWL NHS Foundation Trust** 

020 8962 4546

2 Thorpe Close, London W10 5XL

020 8964 1900

Persian Care Centre

Second Half Centre www.thesecondhalfcentre.com

020 8960 9105



## 2.3 Maintaining independence

#### Staying safe

Many people with dementia feel compelled to walk about or leave their homes, which can be worrying for those around them. 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.

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.

An Occupational Therapist can help find solutions that will keep people safe without losing their independence or dignity. If you believe you could benefit from an assessment from an Occupational Therapist, speak to your GP or contact social services.



#### **Preventing falls**

## Community rehabilitation and falls prevention

People who are at risk of falling, or have problems with walking or balance, can get help from The Royal Borough of Kensington and Chelsea Rehabilitation Service.

#### What the team offers

As well as finding the best service available for you, they also offer:

- An 11 week falls prevention education and exercise group
- A home based exercise programme including strength, balance and walking
- Links to 1:1 physiotherapy through The Royal Borough of Kensington and Chelsea rehabilitation services
- Home environmental risk screening and recommendations, with an occupational therapist
- Coping strategies for falling and learning how to get up from the floor if you do fall
- Falls clinic to explore reasons why you might be falling
- Specialist falls knowledge and training
- Health promotion and education around managing falls and prevention of falls.



(@) intermediatecare@nhs.net

#### Safe at Home

Age UK Kensington & Chelsea provides the Safe at Home Service which provides practical support to people who, due to health conditions or their living and environment, are at risk of falling within their homes. Help with de-cluttering is also provided. The service aims:

- to reduce the risk of falls in the home
- to reduce the risk of harm from other hazards in the home
- to improve the health and wellbeing of the individual.





#### **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. An Occupational Therapist can advise about some of the options available.

The Community Alarm 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 nine 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 to vulnerable adults who would like to feel safer in their own home. The Community Alarm Service can also offer advice about other Telecare systems ranging from flood or smoke detectors to property exit sensors and falls sensors.



@ cas@kctmo.org.uk

#### **Small Repairs Service**

Staying First offers a small repairs service to help people who may not be in a position to do the work themselves. Clients must be over 60 or vulnerable, living in either the Royal Borough of Kensington and Chelsea or the City of Westminster.

Most small repairs are completed within an hour.

The sort of jobs they can carry out includes:

- minor plumbing
- changing light bulbs
- fitting smoke alarms
- glazing and carpentry
- small electrical jobs
- odd jobs
- minor aids and adaptations
- making up flat-pack furniture.

Referrals to the service will be accepted from health and local authority professionals, as well as self referrals.



020 8996 8890



sf.info@sbhg.co.uk

#### Getting out and about

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

#### Having 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.

People with dementia should try to build up other social contacts by attending a day centre or joining a club to keep their social life active. It is also helpful to explain their situation to friends and neighbours so they understand, and encourage them to visit for a chat.

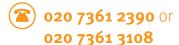
## 2.4 Travel and Mobility

There are a number of transport services within the The Royal Borough of Kensington and Chelsea to help people with mobility problems travel around more easily. You will need to complete registration forms to assess your suitability for these services.

The Taxi Card scheme offers travel by taxi at a reduced rate for a set number of journeys each year.

The Freedom Pass allows free transport on buses, underground and rail services in London for older people and disabled people.

For more information about either of these schemes, contact the council's Accessible Transport Team on:



accessible.transport@rbkc.gov.uk

Dial a Ride provides door-to-door transport for people who find it difficult to use ordinary bus services.

**(2)** 0845 999 1999

www.tfl.gov.uk
and search for Dial a Ride.

#### **Westway Community Transport**

is a local organisation that provides accessible transport options for residents within The Royal Borough of Kensington and Chelsea. These include a Community Car Scheme that provides a car and trained volunteer to help take you to where you want to go, such as to the shops, to see a friend or to an appointment; plus a shopper service, with trained volunteer assistants and a scooter hire service

**2**020 8964 4928

(@) info@westwayct.org.uk

Westway Community Transport, 240 Acklam Road, London W10 5YG

#### **Central London Wheelchair Service**

You may not need a wheelchair all the time but might require one if you are going out and about. It adds that extra degree of mobility and sense of security.

The Wheelchair Service provides mobility equipment to residents in The Royal Borough of Kensington and Chelsea who have serious and permanent difficulties in walking. The service provides a range of equipment, including manual and powered wheelchairs, special seating, cushions and other accessories, and modifications to suit individual needs.

Anyone can make a self-referral or can be referred by a doctor, social worker or nurse. There is a waiting list for an assessment but people with very urgent needs can be seen immediately.

**2**020 8962 3939

wheelchairs@clch.nhs.uk

Specialist Wheelchair Services
Central London Community
Healthcare NHS Trust
306 Kensal Road London W10 5BE

#### 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 individual needs and are usually available throughout the year.



**(2)** 0303 303 0145



info@vitalise.org.uk



www.vitalise.org.uk

#### Key contacts











Central London Wheelchair Specialist Wheelchair Services Central London Community Healthcare NHS Trust

Dial a Ride

Vitalise Essential Breaks



## **Section 3: Care services and** support networks

## 3.1 The Royal Borough of Kensington and Chelsea Adult Services

The Royal Borough of Kensington and Chelsea works in partnership with the local NHS 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 The Royal Borough of Kensington and Chelsea, 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 The Royal Borough of Kensington and Chelsea runs its services. Personalisation is a new way of providing social care services and includes:

- self-assessments
- helping people to maintain their independence
- 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 The Royal Borough of Kensington and Chelsea will try to support this.

If someone is finding it difficult to cope with some daily activities, social services can arrange for 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 to describe their living situation and how they are currently managing.

Help and support will be delivered through The Royal Borough of Kensington and Chelsea's Older 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 to remain at home. Age UK Kensington & Chelsea can help you to fill in a Carer's self assessment form.



020 8960 8137



(@) health@aukc.org.uk



www.aukc.org.uk

#### **Direct Payments and Personal Budgets**

If a person is eligible to receive services from The Royal Borough of Kensington and Chelsea Adult Social Services, 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. Adult Social Services are happy to help people manage these arrangements if they choose.



#### **2** 020 7361 3013

Age UK Kensington & Chelsea can also help you to find a care agency and help to organise your finances, including benefit checks and applications.



#### **2**0 8969 9105



#### (a) information@aukc.org.uk

You can also search for suitable care agencies, including those experienced in caring for people with dementia, on the Care Quality Commission's website.



#### 030 0061 6161



www.cqc.org.uk

#### How to get help in an emergency

If you are worried that you or someone you know is in immediate danger, you should call the police on 999.

If the danger is not imminent, but where the suspected abuse is also a crime, such as assault, racial harassment, rape or theft - you can call the the central police reporting line on **101**.

#### **Getting help from Social Services:**

If you do not think you need immediate help from the police or are worried about calling them, you can call Social Services.

You can talk to social services about your own situation or about someone else you are worried about. You do not have to give your name. You will be listened to, your concerns will be taken very seriously and everything you say will be treated in the strictest confidence.



Social Services Line

020 7361 3013

(Monday to Friday, 9am - 5pm.)



Outside office hours,

020 7373 2227

# 3.2 Community support services

#### Home care

There are a number of home care agencies which can provide help with tasks such as getting up, washing, dressing, or preparing meals. 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 Social Services (see previous section).

If you require an assessment of your needs, contact the Social Services Line.



**(2**) 020 7361 3013

#### Re-ablement services

Sometimes an illness, crisis or a period spent in hospital can affect people's independence and confidence in carrying out everyday activities. The Royal Borough of Kensington and Chelsea'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 three to six weeks. It is available to residents of The Royal Borough of Kensington and Chelsea aged 18 or over.



**(**20 7938 8231

#### **Day Care**

There are some specialist day centres in The Royal Borough of Kensington and Chelsea that provide services for older people with dementia. These include the Miranda Barry Day Centre in Fulham Road, SW10 and the Quest Day Centre (Octavia Housing) in Clarendon Road, W11. All referrals to these day centres are made by social services, psychiatric services or GPs.

They provide cooked meals and snacks plus lots of activities for recreation and physical and mental stimulation. This might include arts and crafts, music and movement, gardening, sing-a-long, quizzes, poetry, library facilities, table games, bingo, exercise classes and some rehabilitation. Various trips and outings are also organised.

Supported bathing facilities are provided, as are access to health checks and advice and support.

There are also other day centres in The Royal Borough of Kensington and Chelsea for older people such as the Pepper Pot Day Centre in Thorpe Close W10, or the Kensington Day Centre in Kensington Park Road, W11 (which will for a time in 2013 be relocated to James Hill House W10 while renovations take place). Although they do not provide a specialist service exclusively 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.

Do feel free to call the Social Services Line for more information about the availability of Day Care and attending a day centre:



020 7361 3013



socialservices@rbkc.gov.uk

#### **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, 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 The Royal Borough of Kensington and Chelsea's care homes.

For more information call the Social Services Line.



020 7361 3013



socialservices@rbkc.gov.uk

Or alternatively, Carers Kensington and Chelsea provide a full information and advice service covering all aspects of caring, including how to find support groups and access respite services.



0800 032 1089



kandc@carersuk.org

#### **Dementia Services**

Age UK Kensington & Chelsea offers a range of services to help support people with dementia and their carers.

These include:

- Dementia Advisor: The Dementia Advisor Service is a continuous point of contact. They can help link people with dementia, their families and carers into services they may require or benefit from along their dementia journey, and help them to navigate their way around the multitude of services. They can also offer information and advice and help people develop strategies to manage their memory at home. A large part of their role is to promote social inclusion – helping to keep people active and engaged in their communities.
- My Memories Cafes are held once a month in the north and the south of the borough, and quarterly on a weekend. These are friendly and supportive get- togethers for people affected by memory difficulties and dementia. Refreshments are provided along with an interesting and fun activity or performance.
- Monthly outings for people with dementia are also organised to local places of interest with support from the Dementia Support Workers and volunteers.
- Creative sessions are held in James Hill House and Miranda House. These involve poetry, art, music, dance and more, and are facilitated by a Dementia Support Worker.

- Ageing Well, Memory Management and Exercise for the Mind groups are facilitated by the My Memories Project Coordinator. These groups aim to teach people strategies to manage their memory, and ways to improve their health and wellbeing.
- One-to-One Dementia Support: weekly home visits are made to support people living with dementia to pursue their interests, maintain independence and retain social contacts.
- Dementia Volunteers: visit people to help them with a particular task, such as accessing a group in the community, sorting paperwork and providing some companionship.

For more information, contact Age UK Kensington & Chelsea's Dementia Team:





# 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 carer's age. Caring for someone with dementia can affect the carer's 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 is a wide range of support available to carers in The Royal Borough of Kensington and Chelsea and this includes:

# The Royal Borough of Kensington and Chelsea Social Services Line

As a carer, you are entitled to a Social Services assessment of your needs. Information and guidance can be provided about benefits, personal budgets, provision of respite, advice and referral to other agencies as appropriate, and details of other carers' groups.



020 7361 3013



socialservices@rbkc.gov.uk

# Carers Kensington and Chelsea

Part of Carers UK, this is the main information and advice service for carers within The Royal Borough of Kensington and Chelsea. They organise advice sessions, a newsletter and a free-phone advice line on:



0800 032 1089



kandc@carersuk.org

#### **Admiral Nurses**

Provide specialised assessment, information, advice and emotional support to carers of people with dementia.



020 3219 0911



info@dementiauk.org

# Crossroads Care, Central and North London

A registered charity providing alternative support for the person that is being looked after so that carers can take a break



020 7485 7416



admin@crossroadscarecnl.org

# Age UK Kensington & Chelsea Carers' Support Group

For carers who look after an older person in The Royal Borough of Kensington and Chelsea. They provide sessions specific to caring for someone with a dementia diagnosis.



020 8960 8137



health@aukc.org.uk

# Age UK Kensington & Chelsea Respite Care

For those caring for an older person over 55 in RBKC. Available in flexible blocks of time.



020 8960 8137



home@aukc.org.uk

#### Time for Me

Time for Me is social, leisure and support activities for carers over 50.



North Kensington and Chelsea **020 8964 1900** 



South Kensington and Chelsea **020 7590 8970** 



🟠 Open Age, 1 Thorpe Close, W10 5XL

#### Portobello Green Fitness Club

Provides reduced exercise rates for carers.



020 8960 2221



community@pgfc.org.uk



3-5 Thorpe Close, W10 5XL

### **Carers' Emergency Card Scheme**

For more information you can contact the Community Alarm Service.



020 7605 6509



cas@kctmo.org.uk

#### Contact<sub>4</sub>Me

A similar scheme to the Carers' Emergency Card Scheme. Your details and those of the person cared for are held on a database, and should anything happen to either of you, someone will call the number you provide on your card, alerting them that someone needs to go to the person you care for, or that you need to be contacted.



0870 389 2299



info@contact4me.com



www.contact4me.com

#### **Carers Direct**

National website and helpline.



0808 802 0202



www.nhs.uk/carersdirect

### **Alzheimer's Society**

Have very useful factsheets and an online carers' forum.



020 7423 3500



enquiries@alzheimers.org.



www.alzheimers.org.uk

# 3.4 Housing and longer term care

# Care options

Dementia is a progressive illness, which means people eventually need more help to manage daily life. The Royal Borough of Kensington and Chelsea is committed to helping its older residents live as independently as possible, for as long as possible. However 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.

#### 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. 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.

There are a number of residential care options in The Royal Borough of Kensington and Chelsea and these are run by the Council or by independent providers such as private companies or voluntary sector organisations.

There are two main types of care home. Some offer accommodation (where residents would normally have their own bedroom with en-suite bathroom and toilet) and food, plus help with personal care such as washing, dressing and going to the toilet. Other homes provide those services and in addition, offer nursing care. Until recently these two types of care home were classified as 'residential homes' and 'nursing homes'.

Homes are registered according to the needs of the people using them, for example, nursing care, dementia care, personal care, mental health support or learning disability support.

They are registered and regulated by the Care Quality Commission (CQC) which is the independent regulator of health and social care provided in England by the NHS, local authorities, private companies and voluntary organisations.

You can search an on-line database of care homes and care agencies at:









# Choosing a care home

Arrangements for care may be made through The Royal Borough of Kensington and Chelsea council, or independently.

If you feel you need financial support from the Council to pay for your residential care, they will carry out an assessment to work out what type of care you need. They will also ask about your finances, because the amount of financial help they can give you depends upon your circumstances.

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.

A trial period is often recommended (usually around six weeks) to make sure it is the right place to meet your needs and this can be discussed with the home's manager.

Contact Social Services for more information about care homes, the assessment process and how to choose a home.



socialservices@rbkc.gov.uk

The Alzheimer's Society has information sheets on choosing long term care.

20 7423 3500

@ enquiries@alzheimers.org.uk

www www.alzheimers.org.uk

The National Careline website also contains useful information and advice about looking for a care home.



0800 0699 784



www.thenationalcareline.org

### The Elderly Accommodation Counsel (EAC)

Is an organisation set up to help older people make informed choices about housing. This national charity operates a First Stop Advice service for information, advice and guidance on any aspect of care, support or housing for older people:



0800 377 70 70



(a) info@firststopadvice.org.uk.



www www.firststopcareadvice.org.uk



Elderly Accommodation Counsel 3rd Floor 89 Albert Embankment London SE<sub>1</sub> 7TP

# **Continuing Care**

NHS continuing care 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 (for example, services from a community nurse or specialist therapist) and personal care (for example, help with bathing, dressing and

laundry). In a care home, the NHS also pays for the care home fees, including board and accommodation.

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 must have a full assessment that looks at the complexity, intensity, severity and unpredictability of their needs for funding to be considered.

For more information, or to see if you are eligible for continuing care, contact the Continuing Care Team or speak to your GP.



020 8962 4225/4973

### **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 the local council and what proportion by the individual.

#### **Palliative Care**

Thinking about how and where one wants to be cared for when seriously ill or dying is not easy. The End of Life Care service in The Royal Borough of Kensington and Chelsea is there to help you consider your options, inform you of your choices and help you to access appropriate care over time. It is also there to ensure that carers receive support during and after the death of their loved one.

The goal of palliative care is to prevent and relieve suffering, and to improve the quality of life for people facing a serious, life-limiting illness. Palliative care services are available in The Royal Borough of Kensington and Chelsea to everyone who needs them and are delivered through a multi disciplinary approach involving GPs, specialist doctors and nurses, community services and through specialist centres such as the Pembridge Palliative Care Centre in St Charles Centre for Health and Wellbeing, Exmoor Street W10 6D7.

If you have an Advance Directive or living will, you may already have specified how vou 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 among the people looking after you so your wishes can be carried out.

If you have any questions or would like to know more, please contact the Pembridge Palliative Care Centre.



**2**020 8962 4406

#### **Kensington and Chelsea Cruse Bereavement Care**

Kensington and Chelsea Cruse Bereavement Care exists to promote the wellbeing of bereaved people and to enable anyone bereaved by death to understand their grief and cope with their loss, regardless of age, religion, disability, gender or sexual preference. The service is free.



**20 8964 3455** 



(a) crusekenchel@btconnect.com



# Key contacts





admin@crossroadscarecnl.org



Elderly A	ccommodation	Elderly
Counsel	Accommodat	ion Counsel
	3rd Floor, 89 Albert Er	mbankment
	Lond	don SE1 7TP
	080	0 377 70 70
	info@firststopa	dvice.org.uk
	www.firststopcaread	dvice.org.uk

crusekenchel@btconnect.com

www.nrststopcareadvice.org.uk		
Pembridge Palliative Care Centre	020 8962 4406	
Open Age	North Kensington	
	and Chelsea	
'Time for Me'	020 8964 1900	
programme	South Kensington	
	and Chelsea	
	020 7590 8970	
ma	ail@openage.org.uk	
Open Age, 1 Tho	orpe Close, W10 5XL	
Re-ablement	020 7938 8231	
Social Services	020 7361 3013	
socialse	ervices@rbkc.gov.uk	
The National Careline	0800 0699 784	
www.the	nationalcareline.org	

# Essential reference and directory Getting information and advice

# The Royal Borough of Kensington and Chelsea's advice, information and guidance network

There are a number of services available within The Royal Borough of Kensington and Chelsea that can provide advice, information and guidance. Some of these services are specific to the Royal Borough while others cover larger areas or are national organisations. Some of the services are specifically for people affected by dementia, while others provide advice, information and guidance across a broad range of topics. If you contact one of these services and they cannot advise you with your problem, they should be able to point you in the direction of someone who can.

#### **Admiral Nurses**

Admiral Nurses are mental health nurses. who specialise in helping the carers of people with dementia 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 3219 0911



info@dementiauk.org

# Age UK Kensington & Chelsea

Age UK Kensington & Chelsea operates a number of specialist advice and home support services for older people, including people living with dementia and their carers. You can contact their Information and Advice Team by telephone, or by visiting their offices from Monday to Friday 9.30am to 5pm. A Wayfinder service is also available, designed to help you find out about local activities and organisations for support and social interaction.



**2**0 8969 9105



(a) information@aukc.org.uk



1 Thorpe Close, London W10 5XL

#### 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

0300 222 1122



www.alzheimers.org.uk

## **Benefit Enquiry Line**

This is a government run national helpline providing advice on welfare benefits, including what you may be entitled to and how to apply. Advice includes disability benefits, mental health and advice for carers.



0800 882 200



www.gov.uk/benefit-enquiry-line

### **Carers Kensington and Chelsea**

Carers Kensington and Chelsea is part of Carers UK and offers local support groups, training activities and information and advice for carers who support someone living in The Royal Borough of Kensington and Chelsea, including carers of people with dementia.



0800 032 1089



kandc@carersuk.org

#### Citizens Advice Bureau

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

There are two offices in The Royal Borough of Kensington and Chelsea; one in Kensington at 140 Ladbroke Grove, W10 5ND (opposite Ladbroke Grove underground station) and one in Chelsea at the Old Town Hall, King's Road, SW3 5EE. The same telephone enquiry line is used for both services.



0844 826 9708

#### **Independent Age**

Independent Age (now merged with 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.



**2** 0845 300 7585

#### **Dementia Advisor**

The Royal Borough of Kensington and Chelsea Dementia Advisor provides advice, information and guidance to people with dementia who live in The Royal Borough of Kensington and Chelsea, and their carers, relatives and supporters. The Dementia Advisor is employed by Age UK Kensington & Chelsea and works closely with the Kensington, Chelsea and Westminster Memory Service, which is run by the local NHS. The Dementia Advisor is a continuous point of contact. They can help link people with dementia, their families and carers into services they may require or benefit from along their dementia journey, and help them to navigate their way through the multitude of services. They can also offer information and advice and help people develop strategies to manage their memory at home. A large part of their role is social inclusion – helping to keep people active and engaged in their community.

The Dementia Advisor can visit people who are living alone or who are housebound. You may be referred to the Dementia Advisor by the Memory Service or you may contact them independently.



020 8960 8137

#### **Elderly Accommodation Counsel**

The Elderly Accommodation Counsel is a national charity whose aim is to help older people make informed choices about meeting their housing needs.



**(2)** 020 7820 1343



www.eac.org.uk



@ enquiries@eac.org.uk



EAC 3rd Floor 89 Albert Embankment London, SE<sub>1</sub> 7TP

#### The National Careline

The National Careline is a national not for profit company offering information about all aspects of care and support for older people, their carers and families, including legal issues, welfare benefits, mobility and choosing care options.



0800 0699 784



www www.thenationalcareline.org

### **POhWER Advocacy Service**

POhWER offers free, confidential and independent advocacy services to people living in The Royal Borough of Kensington and Chelsea, helping people to resolve issues, receive services they need and have their voices heard.



0300 456 2370



) www.pohwer.net



pohwer@pohwer.net

### Royal Borough of Kensington and **Chelsea Social Services Line**

If you have questions regarding receiving care from local Social Services or if you require an assessment of your needs, you can enquire directly through the Social Services line on:



**2**020 7361 3013



socialservices@rbkc.gov.uk

# **Out of Hours Duty Social Worker**

(for emergencies out of normal working hours)



**2** 020 7373 2227



Kensington, Chelsea and Westminster Memory Service	020 3219 0910 42 Westbourne Park Road London W2 5PH
NHS Direct	111
Out of Hours GP and Nursing helplines	020 8969 7777
Community Alarm Service	o2o 76o5 65o9 CAS@kctmo.org.uk
Community Mental Health Team	020 8206 7148
Police	Non-emergency, phone 101 Emergency, phone 999
Care Quality Commission	o3000 616161 Citygate, Gallowgate Newcastle Upon Tyne NE1 4PA
Community Legal Advice (CLA)	0845 345 4345 emailhelp@ communitylegalad- vice.org.uk www.direct.gov.uk
Office of the Public Guardian	o300 456 o300 PO Box 16185 Birmingham, B2 2WH customerservices@ publicguardian. gsi.gov.uk www.direct.gov.uk

Solicitors for the Elderly	o844 567 6173 Sue Carraturo Solicitors for the Elderly Ltd Room 17, Conbar House, Mead Lane, Hertford, SG13 7AP admin@ solicitorsfor theelderly.com www.solicitors fortheelderly.com/
The Law Society	020 7242 1222 www.lawsociety.org.uk
University of the Third Age (London)	o2o 7692 5440 Hampstead Town Hall, 213, Haverstock Hill, NW3 4QP u3alondon@ googlemail.com www.u3a london.org.uk/
Vitalise Essential Breaks	0303 303 0145 info@vitalise.org.uk- www.vitalise.org.uk



**Charing Cross Hospital** 020 3311 1234 Fulham Palace Road, www.imperial.nhs.uk/charingcross London **W6 8RF Chelsea and Westminster Hospital** 020 8746 8000 369 Fulham Road, www.chelwest.nhs.uk London (includes AandE) SW10 9NH St Mary's Hospital 020 3312 6666 Praed Street. www.imperial.nhs.uk/stmarys London (includes AandE) W<sub>2</sub> 1NY The Royal Marsden Hospital 020 7352 8171 Fulham Road, (Cancer specialist) London SW<sub>3</sub> 6JJ, **Royal Brompton Hospital** 020 7352 8121 Sydney Street, London SW<sub>3</sub> 6NP, **Hammersmith Hospital** 020 8383 3074 Du Cane Road. London W<sub>12</sub> oHS. St Charles Centre for Health 020 8969 2488 (includes Urgent Care Centre) and Wellbeing Exmoor Street.

W10 6DZ



#### **Central London Wheelchair Services**

Central London Community Healthcare NHS Trust 306 Kensal Road London, W10 5BE o2o 8962 3939 wheelchairs@clch.nhs.uk

Dial a Ride	0845 999 1999 www.tfl.gov.uk
RBKC Accessible Transport Team (for enquiries about Freedom Passes and Taxi Cards)	020 7361 2390 or 020 7361 3108 accessible.transport@rbkc.gov.uk
Transport for London	www.tfl.gov.uk
Westway Community Transport 240 Acklam Road London W10 5YG	o2o 8964 4928 info@westway.org.uk



**Royal Borough of Kensington and Chelsea** 020 7361 3010

information.services@rbkc.gov.uk

**Kensington Central Library** Phillimore Walk, W8 7RX

Chelsea Library Chelsea Old Town Hall

King's Road, SW<sub>3</sub> 5EZ

healthtrainers@westway.org

North Kensington Library 108 Ladbroke Grove, W11 1PZ

**Brompton Library** 210 Old Brompton Road, SW5 oBS

Notting Hill Library 1 Pembridge Square, W2 4EW

**Kensal Library** 20 Golborne Road, W10 5PF



<b>Chelsea Sports Centre</b> Chelsea Manor Street, SW3 5PL	o2o 7352 6985 chelsea.enquiries@gll.org www.gll.org
Portobello Green Fitness Club 3 – 5 Thorpe Close, W10 5XL	o2o 896o 2221 info@pgfc.org.uk www.pgfc.org.uk
Westway Sports Centre  1 Crowthorne Road, W10 6RP	o2o 8969 o992 or o2o 8969 o993 enquiries@westway.org www.westwaysportscentre.org.uk
Leisure Services Sports Development Team	o20 7938 8182 sportandleisure@rbkc.org.uk
Health Trainers	020 8962 5730



There are a wide variety of community centres within Royal Borough of Kensington and Chelsea. We list a few here that have activities for older residents. Contact the individual centres to find out what they offer.

Al Hasaniya Moroccan Women's Centre Bays 4 and 5, Trellick Tower Golborne Road London W10 5PL	o2o 8969 2292 contact@al-hasaniya.org.uk www.al-hasaniya.org.uk
Al Manaar, Muslim Cultural Heritage Centre 244 Acklam Road North Kensington London, W10 5YG	o2o 8964 1496 info@mchc.org.uk www.almanaar.org.uk
Chelsea Theatre World's End Place, King's Road, SW10 oDR	o2o 7349 7815 admin@chelseatheatre www.chelseatheatre.org.uk
Dalgarno Community Centre  1 Webb Close, Dalgarno Way, W10 5QB	o2o 8969 6300 anna@dalgarnotrust.org.uk
<b>Latymer Christian Centre</b> 116 Bramley Rd, W10 6SU	o2o 8969 2290 office@latymer.org.uk www.latymer.org.uk/regularactivities.htm
New Horizons Centre Guinness Trust Estate Cadogan Street, SW3 2PF	o2o 759o 897o lostasiewicz@new-horizons-chelsea.org.uk www.new-horizons-chelsea.org.uk

Positive Age Centre Peabody Estate Dalgarno Way W10 5JN	o2o 896o 4853 mail@openage.org.uk www.openage.org.uk
Response Community Centre 300 Old Brompton Road London, SW5 9JF	o2o 737o 46o6 info@responseprojects.org.uk www.responseprojects.org.uk
Venture Community Centre 103a Wornington Road, London, W10 5YB	o2o 896o 3234 info@venturecentre.org.uk www.venturecentre.org.uk



Contact Social Services by telephone on o2o 7361 3013, or email socialservices@rbkc.gov.uk to enquire about Day Care.

Miranda	Barry	Dav	Centre
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367A Fulham Road SW10 9TN 020 7349 6890

### **Quest Day Centre (Octavia Housing)**

85 Clarendon Road W11 4XQ 020 7792 8434 info@octaviahousing.org.uk

Kensington Day Centre (Octavia Housing)

24 - 28 Convent Gardens Kensington Park Road, W11 1NJ o2o 7272 7337 info@octaviahousing.org.uk

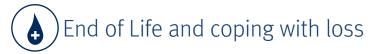
NB: The Kensington Day Centre will be relocated to James Hill House, W10 for a period in 2013 while renovations take place.

#### **Oremi Centre**

(For African and Caribbean people and Arabic speakers who may be in need of mental health support services) Unit 3 Trellick Tower 5 Golborne Road, W10 5PA o2o 8964 oo33 malcolm.philips@rbkc.gov.uk Monday to Friday:9am - 5pm

# **Pepper Pot Day Centre**

1a Thorpe Close, off Ladbroke Grove W10 5XL o2o 8968 6940 info@pepperpotdaycentre.co.uk



Cruse Bereavement Care	o2o 8964 3455 crusekenchel@btconnect.com	
Pembridge Palliative Care Centre	020 8962 4406	
<b>Kensington and Chelsea Register Office</b> Chelsea Old Town Hall King's Road, SW3 5EE	o2o 7361 4100 chelsea.registeroffice@rbkc.gov.uk	
National Association of Funeral Directors	0845 230 1343	



www.adviceguide.org.uk	www.nhsdirect.nhs.uk
www.aukc.org.uk	www.openage.org.uk
www.alzheimers.org.uk	www.publicguardian.gov.uk
www.citizensadvice.org.uk	www.rbkc.gov.uk/ healthandsocialcare
www.cqc.org.uk	
www.independentage.org	
www.thenationalcareline.org	