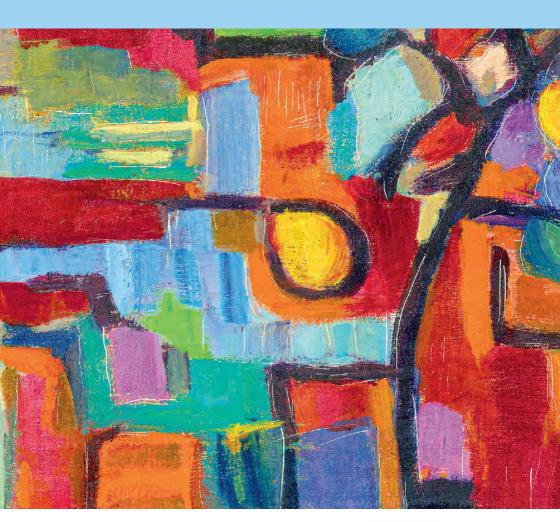
# **Living with Dementia**

Getting help in Hammersmith & Fulham















Become a 'Dementia Friend' to increase awareness, supporting Hammersmith and Fulham to become a dementia friendly community.

www.dementiafriends.org.uk

Cover artwork: 'Towards Abstraction' by Greta Chaffer, an artist, carer and resident of Hammersmith and Fulham

Booklet design: Richard Pierce 

✓ sarich354@gmail.com

Dementia affects more people each year. Many of us have experienced its impact on family members and those we know.

As a council, we are committed to making lives easier for people who are living with dementia, and for their family and carers.

We know how difficult it can be to navigate dementia – from getting a diagnosis to getting support.

That's why at the last election, we pledged to create a dementiafriendly community in our borough.

We said we would work with the NHS to increase diagnosis and trained staff.

We committed to building dementia-specific and dementiainclusive activities that give choice and control and reduce social isolation.

And we undertook to provide clear, accessible information about how to get services and support – that's what this guide is all about.

You will find here the wide range of services and support available locally for people living with dementia, and their family and carers.

I'm hugely grateful to H&F's resident-led H&F Dementia Action Alliance for their support in producing the guide, which builds on the excellent Dementia Strategy that they co-produced with the community and council.



**Ben Coleman**Deputy Leader
Hammersmith & Fulham Council

# This guide has been designed to give you an overview of local resources and to help you find the services and support you need

If you or someone you know has just been diagnosed with dementia you may have many questions. Dementia is the term used to describe changes in cognitive functioning, for example, memory, attention and thinking skills.

There are many conditions and types of dementia. The way people are affected and treated will depend on the specific disease that is causing the dementia. There are a range of resources available online that can provide more detailed information about health and well-being. We suggest that you find out more about your own condition and refer to the information available from national NHS, visit:

www.nhs.uk/conditions/dementia

And other organisations such as the Alzheimer's Society (see page 20) and Dementia UK (Admiral Nurses) (see page 23).

This booklet has been written to provide guidance on how to access local resources and services. The Dementia Action Alliance is working closely with the borough of Hammersmith and Fulham and the NHS to support people to live well with dementia.

#### There are key things to know about dementia:

- 1. Dementia affects people in different ways and can be challenging for people with a diagnosis as well as for their carers, friends and family.
- 2. Dementia is not just about losing your memory, there are other symptoms like difficulty in making decisions or losing your balance.
- **3.** It is possible for those affected by dementia to experience positive emotions and enjoy a good quality of life.
- **4.** "Life goes on and there's plenty of living to do." John, resident living with dementia
- 5. "There is more to the person than the dementia. I am still the same person I was before my diagnosis."
  Jane, resident living with dementia
- 6. You are not alone.

# What you'll find inside this guide

Getting a timely diagnosis	Page 8	SECTION 6 Assistive Technology	Page 38
SECTION 2 Help after diagnosis	Page 12	SECTION 7 Research opportunities	Page 41
SECTION 3 Support for carers	Page 23	SECTION 8 Going into hospital	Page 44
SECTION 4 Legal and financial matters	Page 31	SECTION 9 Additional information, help and advice	Page 46
SECTION 5 Health and Social Care	Page 34		1 0,50 10
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# **Getting a timely** diagnosis

## Signs and symptoms

Some people know they are having difficulties with their memory, others may seem unaware.

Look out for difficulty with short-term memory, problem solving, planning ahead, losing motivation, struggling to find words and to carry out every day tasks.

#### Benefits of an early diagnosis:

- allows access to medication which may be able to delay the advancement of symptoms
- you can plan for the future
- you can qualify for certain benefits and support
- you can live independently for longer



### **STEP** Make an appointment with your NHS GP to discuss your concerns about your memory

It is always a good idea to bring a friend or family member along with you to jot down some notes or remind you of any questions you want to ask the Doctor.

### **STEP** Symptoms of dementia can be similar to other conditions which can be easily treated

It is possible that 'dementia symptoms' can be caused by other conditions such as an infection, diabetes, a vitamin deficiency, depression or anxiety. A GP's prompt review allows you to get the correct support sooner.

## What to expect during an assessment by your GP

Initial investigations are made which can include blood tests (ask to have the blood sample taken at the surgery if possible), heart tracing and a personal and medical history about how you have been getting on.



## Referral to the 'Memory Clinic'

St. Vincent's Hospital, 49 Caroline Street, London W6 9QH

0208 483 2525

A specialist team of healthcare professionals provide assessment, diagnosis and treatment for residents referred by their GP.

A comprehensive initial assessment will be done. Following that visit, a further brain scan and other tests or visits to other consultants may be scheduled.



#### An appointment to review the tests

A meeting will take place to discuss the treatment which may be medication, therapeutic or relating to your care needs, and make a care plan.

#### Diagnosis elsewhere

If your diagnosis is not by the Memory Clinic, but for example by your hospital doctor or private doctor, you must get a referral from your NHS GP to access the services and support of the Hammersmith and Fulham Dementia Link Worker from the Memory Clinic.



# Dementia link worker will be allocated to every person given a diagnosis

They have specialist expertise in dementia, as well as knowledge of local council, NHS and voluntary sector services. The link workers will help people with dementia and their carers to access services that can help them maintain their physical health and wellbeing which may include Cognitive Stimulation Therapy, Occupational Therapists, Speech Therapists, Community Psychologists, 1:1 sessions.

#### **Memory Clinic**

The 'Memory Clinic' is formally known as the Cognitive Impairment Dementia Assessment Service (CIDS).

It is part of the Hammersmith and Fulham Older Persons Mental Health Service (HF OPMHS), operated by a specialist team from West London NHS Trust, supporting people of any age who are experiencing signs and symptoms of dementia.



# Help after diagnosis

We know that different people react differently to being diagnosed - some may feel relieved after getting a diagnosis as it gives a reason for the changes that have been taking place.

For others, the reality of the diagnosis can come as a heavy blow.

'Adjusting to the new reality' starts with understanding. The right information can explain what dementia is and how it is likely to impact the person with dementia and everyone in their life - friends, family and carers.

# 12 Practical suggestions to do now

- 1. Make contact with our local dementia support service at the Alzheimer's Society, it's free and allows you to take advantage of services and support groups offered (see page 20).
- 2. Register to join Carers Network, it's free and gives you access to specialty advice about your rights and benefits, counselling, activities and end of life support (see page 25).
- **3. Tell your GP if you are a carer** as soon as possible in order that you can be better supported as an unpaid carer.

- **4. Set a routine for yourself**, going out at least 3 times a week to participate in a group activity where you socialise with others in the community. Engage with a variety of activities like singing or art.
- **5. Request a Carer's Assessment.** Review eligibility for benefits including request for Carer's Assessment (see page 27).
- **6.** Learn about the Careline Emergency Home Response Alarm Service (see page 40).
- 7. Make a Will and Lasting Power of Attorney and make sure this is done while you are still able to make choices about your future care and finances (see page 31).
- **8.** Focus on a healthy diet and make a meal plan with a low fat, low sugar diet you can cook yourself. Drink regularly to avoid dehydration.
- 9. Keep a simple diary of the doctors appointments and the number of hours spent by people in the role of carer, noting the help you need and how that level of support has changed over time.
- **10. Stay positive by keeping physically active**, try walking daily for 20 minutes.
- **11. Contact the Dementia Action Alliance** for a copy of Living with Dementia Getting help in Hammersmith & Fulham.
- **12. Get involved in research**, it gives the benefits of meeting new people and helping research (see page 41).

# **Young Onset Dementia**

Someone is said to have young onset dementia if they develop symptoms before the age of 65. Diagnosis can be delayed because the symptoms may not be recognised as dementia.

We know that in the case of young onset dementia you may be working; your partner may be employed, you may have dependent children, be supporting older parents, have ongoing financial commitments and be physically fit and active.

# 'Good Life with Dementia' programme

A seven week programme run by Innovations in Dementia with the Memory Clinic and Dementia Action Alliance for people with a recent diagnosis of dementia.

The programme provides information and support and includes sessions on daily living aids, planning for the future and emotional resilience all led by people who have been living with the condition for some time.

Your Dementia Link Worker from the Memory Clinic or Dementia Action Alliance can provide more information.

≥ info@hfdaa.org

# 'Good Life with Dementia' Peer Support Groups

The group meets monthly and is open to anyone with dementia looking to gain the benefit of meeting people in a similar situation - sharing information and peer support.

Follow-on gatherings for residents who have gone through the Good Life Programme having shared experiences, knowledge and support with others in a similar situation, providing an essential support network to help people with dementia learn coping strategies to manage their condition and avoid becoming isolated.

info@hfdaa.org

## **Memory Cafes**

#### **H&F Tuesday Club - Network of Memory Cafes**

The cafes are a place for people with dementia and/or their carers, to meet in a fun welcoming environment. People can share experiences, access information and enjoy spending time together, while enjoying a cup of tea and amusement.

HF Dementia Partnership Board are running a programme of events at four memory cafes called The Tuesday Club. Three open on a Tuesday and one is open on a Saturday.

Each cafe takes place at a different venue in a different part of the borough and has its own distinct atmosphere/character. Try them all. Outside speakers will be organised as requested.

#### Contact Peggy:

**\** 0777 578 4520

≥ peggy@hfdaa.org

The Tuesday Club Memory Cafes take place at:

#### Nourish Hub

Supported by Dementia Action Alliance

Held on the 1st Tuesday of every month.

Swanscombe House 1 St Ann's Road London W11 4SS

**U** 11:00am - 1:00pm

0207 967 1302

#### Age UK Hammersmith & Fulham

Supported by Visiting Angels Home Care

Held on the second Tuesday of every month.

105 Greyhound Road London W6 8NJ

3 11:00am - 1:00pm

0207 386 9085

#### Elgin Close Resource Centre

Supported by Walfinch Independent Home Living Held on the third Tuesday of every month.

1-3 Elgin Close, off Goldhawk Road, London W12 9NH

① 11:00am - 1:00pm

**\** 0203 815 2184

#### Alzheimer's Society

Held on the **last Saturday** of every month, for a weekend choice.

49 Queen Caroline Street, Hammersmith W6 9QH

0 2:00pm - 4:00pm

**\** 0208 563 0001, Monday - Friday

Mammersmith-fulham@alzheimers.org.uk

# Hammersmith and Fulham Dementia Action Alliance

The Hammersmith and Fulham Dementia Action Alliance (HFDAA) brings together local organisations, businesses and charities in the borough. It offers people from the community a chance to learn more about how to support dementia awareness and make a contribution to improve the lives of people living with dementia and their families, whether they live, work or spend leisure time in the borough.

info@hfdaa.org

## For Brian, C.I.C

For Brian CIC operates in north Hammersmith with and for people with dementia, their families and friends, and a growing team of creative practitioners.

Bespoke support is co-produced with each individual and their support networks; activities include:

- Weekly all ability cycling sessions with instructors and cycle taxi
- art, song writing and dance workshops
- technology support
- information, advice & counselling
- inclusive street parties
- 0754 528 7139
- clare@forbrian.co
- www.forbrian.co



#### **DanceWest**

Since 2014, DanceWest seeks to promote wellbeing through physical activity and creative expression. **Dance for Dementia** is a weekly dance programme, which combines physical and cognative stimulation with fun routines.

Sands End Art and Community Centre (dance studio) Peterborough Road, London SW6 3EZ

**\** 0749 451 3079

□ admin@dancewest.co.uk

wwwdancewest.co.uk

## **Turtle Key Arts**

Turtle Key Arts is a local charity founded in 1989.

**Turtle Song** has been held regularly since 2008, it is a 10 week series of workshops for people with dementia and their companions (carers, friends and family) with a professional composer, director and musicians.

0208 964 5060

charlotte@turtlekeyarts.org.uk

# **Alzheimer's Society**

#### These are local services and support

#### 1. St Vincent's Day Centre

People with a dementia diagnosis take part in a range of activities and socialise in a familiar surrounding. Transport and lunch is included.

Monday - Friday, 10:00am - 3:00pm

#### 2. Dementia Support

Trained staff provide 1:1 information, advice and support to people with, or approaching, a diagnosis of dementia and their carers, family and friends.

Monday/Wednesday/Friday, 9:00am - 4:00pm

#### 3. Carer Peer Support

This group offers carers the chance to take time off for themselves, meet other carers and share experiences.

 Held every two weeks, alternate Wednesdays and Fridays, 12:30pm - 2:00pm

# 4. Memory Cafe (part of Tuesday Club network of weekly Memory Cafes)

Monthly gathering for social interaction and providing information to people with a dementia diagnosis and their carers.

Held on the last Saturday of every month,2:00pm - 4:00pm

For enquires and self-referrals for any of the above, contact:

- Monday Friday, 9:00pm 5:00pm
- 0208 563 0001
- Hammersmith-fulham@alzheimers.org.uk

# **National Alzheimer's Society Resources**

#### Dementia Support Helpline

If you are affected by dementia, worried about a diagnosis or a carer, trained staff are ready to give you the support you need.

Opening hours:

Monday - Wednesday, 9:00am - 8:00pm Thursday - Friday, 9:00am - 5:00pm Saturday - Sunday, 10:00am - 4:00pm

**\** 0333 150 3456

#### Talking Point

Dementia Talking Point is an online community where anyone can seek support. It's free, open day or night, and can be accessed online.

www.alzheimers.org.uk/get-support/dementia-talking-point-our-online-community

#### Publications and Factsheets

There is a wide range of publications and factsheets designed to support and inform anyone affected by dementia.

www.alzheimers.org.uk/get-support/publicationsfactsheets



#### **SECTION 3**

# **Support for carers**

Many people do not see themselves as carers straight away, they are simply doing what 'needs doing'.

A carer is someone who provides help and support to a partner, child, relative, friend or neighbour, who could not manage without their help due to frailty, illness, disability, a mental health condition or substance misuse. The care they provide is unpaid.

### **Dementia UK, Admiral Nurses**

Dementia UK provides specialist nurses, known as Admiral Nurses, giving expert advice and information. They offer emotional support and understanding for the carers and families of people with dementia, during all stages of dementia.

Book an appointment on your computer or smart phone or call the helpline.

- Monday Friday, 9:00am 9:00pmSaturday Sunday, 9:00am 5:00pm
- 📞 0800 888 6678 (Helpline)
- Mark helpline@dementiauk.org

## **Carer's Assessment**

To help you if you spend a regular amount of time looking after or supporting someone, who would otherwise be unable to live independently, a Carer's Assessment will review what are your needs outside of being a carer, and what will help you in your caring role.

To get a Carer's Assessment contact Carers Network:

- 0208 960 3033
- carers@ carers-network.org.uk

Or call Hammersmith and Fulham Social Services:

- O Monday Friday, 8:45am 5:00pm
- 0800 145 6095

If you choose to get the Carer's Assessment by Hammersmith and Fulham Social Services, ask to have a 'needs assessment' for care at the same time.

## **Young Carers**

Advice for someone under 18 in a caring role.

www.nhs.uk/conditions/social-care-and-support-guide/ support-and-benefits-for-carers/being-a-young-carer-yourrights

#### **Carers Network**

Since 1991, the charity has been supporting unpaid carers aged 18 or over, in London.

- Monday Friday, 9:00am 5:00pm
- **\** 0208 960 3033
- ✓ info@carers-network.org.uk

Offers several specific services for carers of people living with dementia including carers assessments, legal help and advice, money and benefits, employment and further education, health and wellbeing and end of life carers project.

- Carers Network has a counselling service available. Sign up in case there is a waiting list. This is a very popular service.
- Monthly H&F Carers Coffee Mornings (check website or newsletter for location and dates), you can borrow activity products specially designed for people with dementia, as part of their innovative Bizzy Box Lending Project.
- Monthly Advice Drop-In for H&F Carers

Check website or newsletter for location and dates.

For more information about workshops and training to help carers within their caring role, leisure, and work skills, visit:

www.carers-network.org.uk

#### **Time Out for Carers**

As a carer you can become lost and your life can be turned upside down. It is important to take regular time out for yourself and connect with support/social groups to maintain balance in your life. At times maintaining the balance can be one of the biggest challenges.

Dee Morrison, a psychotherapist and carer, has combined her professional skills and her experience of caring for her mother, who is living with dementia, to create a flexible five week course which provides space for carers to come together, to talk, to be supported, whilst promoting wellbeing through self-care, fun and creativity.

The course can be delivered online, face to face or a combination of both, based on the need and preference of participants.

#### The course covers:

- 1. Identity
- 2. Dealing with services
- 3. Challenges with family
- 4. Relationships
- 5. Self-care

For course dates, visit:

www.nubianlife.org.uk

#### Alzheimer's Research UK

A dementia and Alzheimer's disease research charity in the UK which offers medically approved information including 'Dementia Explained' that has been developed by Alzheimer's Research UK to help children and teenagers understand dementia, how it affects someone and how this could impact their lives, visit:

www.alzheimersresearchuk.org/kids/dementia-explained

If you have questions about dementia, want to know more about dementia research or about how you can get involved in studies, the information officers on their Dementia Research Infoline can help you.

- Monday Friday, 9:00am 5:00pm
- **\** 0300 111 5111

# **Respite Care**

Respite care means taking a break from caring, while the person with dementia you care for is looked after by a trained professional.

There are different types of support for which you may be eligible including day care, a short stay in a care home, befriending, homecare to allow you to get a good night's sleep.

(See Health and Social Care on page 34)

## **Day Centres**

Places for adults who need extra support to take part in activities, catch up with friends, and have lunch and a cup of tea, giving carers a well-deserved break.

#### St Vincent's Day Centre

For residents with a dementia diagnosis, run by the Alzheimer's Society.

49 Queen Caroline Street Hammersmith W6 9QH

- Monday Friday, 10:00am 3:00pm
- 0208 563 0001
- ≥ mel.randall@alzheimers.org.uk

#### Imperial Wharf Resource Centre

Olive House 185 Townmead Road London SW6 2JY

- Monday Friday, 8:30am 4:00pm
- 0207 384 6950
- Marid.penna@lbhf.gov.uk

#### Elgin Close Resource Centre

1-3 Elgin Close, off Goldhawk Road London W12 9NH

- Monday Friday, 9:00am 5:00pm
- 0208 381 5003
- ✓ funke.johnson@housing21.org.uk

#### Nubian Life Resource Centre

For African, Caribbean and Asian elders, including residents living with complex health conditions.

50 Ellerslie Road, London W12 7BW

- Monday Thursday, 9:30am 3:30pm
- **\** 0208 749 8017
- ☑ Jazz.browne@nubianlife.org.uk



## **Befriending**

There are a number of local organisations offering befriending services.

Here are some of the organisations which offer a variety of befriending, over the phone, in person, or activity based:

- Age UK Hammersmith & Fulham
- Creighton Centre (previously known as Bishop Creighton House)
- Fulham Good Neighbours
- The Masbro Centre
- Richmond Fellowship

(see **Additional Information** on page 46 for contact details)



#### **SECTION 4**

# Legal and financial matters

## Important legal planning ahead

To help you feel more confident for the future you should discuss your wishes for expected care and finances well in advance of difficulties making decisions and make a:

- Last Will and Testament.
- Lasting Power of Attorney.
- Living Will sets out a persons desires about future medical treatment in case you can no longer give informed consent.

#### Hammersmith and Fulham Law Centre

Free legal advice and representation relating to asylum, employment, housing, welfare benefits and immigration.

Hammersmith Library - First Floor Shepherds Bush Road, London W6 7AT

- Monday Friday, 10:00am 1:00pm, 2:00pm 5:00pm
- **\** 0203 880 1727 (leave a voicemail)

#### **Benefits and concessions**

Both the person with dementia and the carers could be entitled to receive new benefits.

To arrange an online benefits check, visit:

- advice@carersuk.org
- www.gov.uk/benefits-calculators
- Carer's Allowance, if you care for someone at least 35 hours a week.
  - **\** 0800 731 0297
  - www.gov.uk/carers-allowance/how-to-claim
- Attendance Allowance, not means tested, extra money if you have a long-term condition or disability and have needed help for more than 6 months.
  - **\** 0800 731 0122
- Blue Badge, parking in LBHF
- Free Bus Travel Card, LBHF
- Disability Persons Railcard
  - 0345 605 0525
- Personal Independence Payment (PIP), if you have a longterm condition or disability and are under the state pension age.
- Council Tax Rebate
- Carer's Personal Budget, LBHF

- Continuing Health Care (CHC), some people with long term complex health needs qualify for free care.
  - Eligibility depends on assessed needs during a 2 step process by health and social care professionals.
- Carer's Grant

#### **LBHF Welfare Benefit Advice Service**

Hammersmith and Fulham residents can call or email for advice:

- Monday, Wednesday, Friday, 9:30am 12:30pm and 1:30pm - 4:30pm
- 0208 753 5566
- welfare.benefit@lbhf.gov.uk

Referral by social worker:

- **\** 0208 753 5343
- folashade.odejimi@lbhf.gov.uk

#### Specialist advice

Specialist advice is recommended when filling out benefit forms. Some benefits depend on many factors which an adviser can help you understand.

- Citizens Advice (see page 49)
- Action on Disability (see page 46)
- Age UK (see page 51)
- Admiral Nurses (see page 23)

# **Health and Social Care**

# LBHF Adult Social Care (ASC)

ASC is the part of Hammersmith and Fulham Council, helping you with daily living and maintaining independence.

- Monday Friday, 8:45am 5:00pm
- ASC Main Number: 0800 145 6095
   Out of Hours Emergency: 0208 748 8588
- adultsocialcare@lbhf.gov.uk

Get information online about services and support from:

beta.lbhf.gov.uk/living-independently

If you do not have internet access, call the Freephone number above for further support.

# 'Needs' Assessment for Care (for the person with care needs)

A meeting between the person with dementia and a care professional to understand what type of support is needed to live independently (not means tested).

- Monday Friday, 8:45am 5:00pm
- **\** 0800 145 6095

#### Home care service

For residents assessed as needing support in order to remain living at home (free for elderly and disabled residents).

If you are eligible for home care, a personal budget and use of direct payments will be discussed with you and your carer. Also:

- Equipment and adaptions to your home, for example railings, ramps, trolleys.
- Help with walking and mobility, physiotherapy, mobility aids and wheelchairs, falls prevention classes.
- Community Independence Service (CIS), reablement service provides home based support after medical treatment to regain your independence, and provides care to avoid hospital admission.

#### Careline

A 24 hour emergency home response alarm service which provides residents with a pendant which can be pressed to alert an emergency response.

There may be a charge for the Careline service if it is not covered by the Social Care Needs Assessment.

- Quantification
  24 hours a day, 7 days a week
- 0208 741 4008
- careline@lbhf.gov.uk

#### **Health care**

#### 1. Primary care

The GP is responsible for the overall management of your healthcare needs and the gateway to other services such as:

- Onward referral to specialist services (e.g. physiotherapy)
- Medication reviews and annual reviews
- End of Life care for referral to Palliative Care Support
- Urgent Care Plans (formerly called Advanced Care Plan)

#### Talking to your GP and NHS Health Check

It is important for carers to look after their own physical and mental health.

- A. Tell your GP you have caring responsibilities. Your GP can signpost local continence services, patient transport to hospital appointments, can arrange home visits and 'double' appointments for both the you and the 'cared for', and can access the help of District Nurses who visit people in the home.
- B. NHS Health Check is free, every 5 years, for people who are between the ages of 40-74. Health checks can detect certain health problems, whether you are at higher risk, and advise on how to prevent them, for example, heart disease, diabetes, kidney disease and stroke.

#### 2. Community Independence Service (CIS)

You may be referred to the Community Independence Service (CIS). This is a community healthcare service that provides advanced short-term nursing care, occupational therapy, physiotherapy and social care to people with immediate health or functional needs.

The service aims to offer safe care at home which enables people to avoid unplanned hospital admissions.

CIS is available seven days a week from 8:00am to 10:00pm for adults over 18 who reside in (including nursing and care homes) and are registered with a GP in Hammersmith and Fulham.

- 0300 033 0333
- cnwl.cis3borough@nhs.net

#### 3. District nursing

District nurses work in people's homes and the local community to help patients improve, maintain, and recover their health, cope with health problems, and achieve the best possible quality of life, whatever their disease or disability.

District Nurses treat a number of conditions including managing chronic long term conditions, medication management, wound care management and advice, continence problems, and can refer to other services.

- **\** 0300 033 0333
- Out of hours: 020 8969 7777
- www.clch.nhs.uk/services/district-nursing

# **Assistive Technology**

#### What is Assistive Technology?

Assistive Technology is an umbrella term for any device which assists a person in retaining or improving their independence, safety, security and dignity.

# What is the difference between Assistive Technology and other forms of community equipment?

Assistive Technology mainly focusses on, but is not limited to, devices that make communication easier in the event of an emergency situation, devices that communicate information back to the user, such as reminder devices, devices that can help prevent critical incidents occurring in a person's home, such as fire or flood, and devices that can make a person safer whilst out in the community, such as GPS 'safer walking' devices.

#### Who can benefit from Assistive Technology?

Anyone who has a medical condition or disability that limits their ability to engage in daily activities or respond appropriately in an emergency situation.

#### What kind of equipment may be available:

- Telecare alarm units linked to LBHF's Careline Service. These alarms can have many different devices connected to them, including 'pendant' alarm triggers, fall detection devices and environmental sensors.
- Devices that can automatically alert to a fall taking place, such as sensors used to determine if a person has left their bed and fallen at night.
- Environmental sensors linked to the LBHF Careline service, such as telecare smoke detectors, heat detectors, carbon monoxide sensors and flood sensors.
- Reminder devices, such as medication reminders, that can help people to maintain their independence.
- GPS devices that can help improve a person's safety whilst out in the community.
- Devices that can monitor a person's wellbeing, without the need for video cameras or other intrusive forms of technology.
- Devices that can monitor certain types of medical condition, such as epilepsy.

#### How can I get this technology?

The Hammersmith and Fulham Careline service is available to anyone aged 18 or over, and is not dependent on the person having social care support. Referrals can be made by anyone, including the person receiving the service, family or friends, although if the person is being referred to Careline by a third party, they must provide their consent to the referral taking place.

Other devices, such as telecare heat and smoke detectors, GPS devices, fall monitoring devices, are not provided directly by Careline, but may be provided as part of the outcome of a LBHF Social Care 'Needs' Assessment. If not, there may be a charge for the Careline service.

© 24 hours a day, 7 days a week

**\** 0208 741 4008



#### **SECTION 7**

# **Research opportunities**

#### Why participate in research?

"Without the contribution that volunteers make by taking part in research, progress in dementia just wouldn't be made".

Alzheimer's Research UK.

The global research community are working on ways to prevent, detect, and treat dementia. Engaging in research networks comes with exciting opportunities to learn about cutting-edge science, and meet new people from different backgrounds. Your insights will directly help improve the accessibility of scientific research and shape the way that people affected by dementia are treated and supported in the future.

#### Research in Hammersmith and Fulham

Hammersmith and Fulham are a research-active community, with strong links to university partners at Imperial College London, the UK Dementia Research Institute (UK DRI) and the National Institute for Health and Social Care Research (NIHR).

There are many opportunities for residents to get involved.

Join Dementia Research (JDR). The JDR is a national platform that lets the research community know you are interested in getting involved.

www.joindementiaresearch.nihr.ac.uk

**Voice.** Researchers need to hear from you. Voice has been set up to bring researchers in contact with the public in general and patients (users of healthcare). This is an essential step in the development of research and helps researchers think about and focus on things that matter to you. They also want to know your thoughts on the design and delivery of their studies. Good design means that people are more likely to enrol in research and stay enrolled. The Voice will circulate invitations to join online and face to face discussions and workshops lasting 1-2 hours with reimbursement offered for your time.

voice-global.org

**UK Dementia Research Institute Care Research and Technology (UK DRI CR&T).** Based at Imperial College London in White City, the UK DRI CR&T has been investigating the use of technology to support the health needs of residents living with frailty, dementia, and complex neurological conditions. The Centre is committed to involving and engaging members of the community, and often hosts public events about ongoing research. To stay connected and meet others developing the next generation of digitally-enabled care, join the mailing list:

www.imperial.ac.uk/uk-dri-care-research-technology/joinus/friends-of-crt Clinical trials. You may hear about clinical trials through your NHS healthcare teams or Memory Unit at Charing Cross Hospital or West London NHS Trust. They will either give you information directly about a study or ask if you are happy to be added to a research register so that they can contact you in the future if you are eligible for future drug trials.

**0203 311 5228** 

www.imperial.nhs.uk/research/imperial-memory-unit

The Health Research Authority (HRA) protects and promotes the interests of patients and public in health research. It sets out strict standards to ensure that research is carried out ethically and safely. To learn more about their work, visit their website.

www.hra.nhs.uk/about-us/what-we-do

#### To find out more about research and dementia, visit:

- www.alzheimers.org.uk/research
- www.alzheimersresearchuk.org/research/about-our-research
- www.nihr.ac.uk/patients-carers-and-the-public

# **Going into hospital**

A visit to hospital can be challenging for a person with dementia and for their carers.

The noise, the bright lights and the hustle and bustle of new surroundings can add to the pressures of an unfamiliar environment. So preparing ahead should help you deal with any planned or emergency hospital stay.

#### **Useful advice**

- Before going to hospital, remember to leave your Careline pendant at home, so it does not get lost.
- Pack a small bag with pyjamas, extra medication, extra pair of glasses. Be sure to label everything with a name using inedible marker or a sew on name tag.
- Do not assume that any of the hospital staff know that you or your 'cared for' has dementia. You should fill out the 'WHAT MATTERS' yellow sheet and take it with you. This will be displayed by the patient's bed.
- Ask if the hospital has a dementia team or an Admiral Nurse who can support during the hospital stay. Find out if the hospital has activity kits, or support materials to reduce anxiety or distress.

- The Imperial College Healthcare Trust hospitals offer carers access, at all times, to the person with dementia. Please ask for a Carer Passport.
- Having a Lasting Power of Attorney in place is very important if a decision needs to be made about health care. Bring documentary proof of the Lasting Power of Attorney to show the staff.
- Make sure you tell nurses and other care staff:
  - 1. If the person with dementia has had any previous experiences which might make them worried in hospital.
  - 2. If the person with dementia has problems with pain, explain what is done at home to help.
  - **3.** What are the routines around eating and drinking? Does the person with dementia have any problems with swallowing?
  - **4.** The patient needs support to eat meals (bite sizes, food texture, allergies, likes/dislikes).
- Ask the doctors and nurses about medications and any changes they make to instruction about dosage, what time of day, and whether taken with food or before.
- Start considering options for discharge early on. Departure from hospital should take place before 6:00pm.

# Additional information, help and advice

Always ask for information in the language which is easiest for you to understand

## Action on Disability Centre for Independent Living - Welfare Benefits and Direct Payment support services

Provides independent advice on benefits and services available to people with all disabilities, including dementia, and their relatives.

Ground Floor Office, Mo Mowlam House Clem Atlee Court, London SW6 7BF

**\** 0207 385 2098

info@aod.org.uk

#### **Advocacy specialty services**

There are several advocacy services available to support people to make informed decisions and secure the rights and services to which they are entitled. The Advocacy Project provides many types of support for residents of Hammersmith and Fulham:

- Who lack capacity to make certain decisions or do not have the capacity to agree to the proposed arrangements through the Independent Mental Capacity Advocate (IMCA).
- Who want to express concerns about treatment including representing and advocating at meetings through the Independent Mental Health Advocacy (IMHA).
- Who want to use the free, confidential and independent NHS Complaints Advocacy.
- Monday Friday, 9:00am 5:00pm
- **\** 0208 106 1500
- info@advocacyproject.org.uk



#### Care homes in Hammersmith & Fulham

#### The Chiswick Nursing Centre

Ravencourt Gardens London W6 0AE

**\** 0208 222 7800

### Farm Lane Care Home (part of Care UK)

25 Farm Lane London SW6 1PX

0203 504 4132

#### Nazareth House Hammersmith

169-175 Hammersmith Road London W6 8DB

0208 748 3549

## St Vincent's House Care Home (part of Care UK)

49 Queen Caroline Street London W6 9QH

**\** 0203 504 5909

# Citizens Advice - Hammersmith and Fulham

Free legal advice and representation relating to debt, employment, housing, welfare benefits, consumer rights, carer's allowance and attendance allowance.

O Monday - Friday, 10:00am - 4:00pm

0808 278 7832

www.cahf.org.uk

#### Drop in:

Charecroft Community Hall Shepherds Bush London W12 8PQ

U Tuesday, Wednesday, Thursday, 10:00am - 4:00pm

Avonmore Library North End Road London W14 8TG

Monday, Wednesday, Friday, 10:00am - 2:00pm

#### **Continence care**

Information and advice about urinary and bowel incontinence.

www.ageuk.org.uk/information-advice/health-wellbeing/ conditions-illnesses/incontinence

# **End of Life planning - Palliative care, Advance care planning**

#### Carers Network

Offers specialist advice for carers looking after someone approaching the end of their life.

0208 960 3033

#### Carers UK

www.carersuk.org

#### Marie Curie

Information and support services helping people through all aspects of dying and bereavement.

**\** 0800 090 2309

www.mariecurie.org.uk

#### Royal Trinity Hospice

30 Clapham Common North Side, London SW4 ORN

**\** 0207 787 1000

#### **LBHF Advice**

General information and advice.

145 King Street, London W6 9XY

🕓 Monday - Friday, 9:00am - 5:00pm

**Q** 0208 753 4198 (Option 3)

#### **LBHF Housing Benefit and Council Tax Support**

Customer service centre is open for appointments online or over the phone. If you need further assistance, please ask for it.

Monday - Friday, 9:00am - 5:00pm

0208 753 6681

#### **Providers of Older Persons Services (POPS)**

Here are a few of the POPS organisations in the borough. See their websites for further information.

#### Age UK Hammersmith and Fulham

Activities, learning, advice about benefits and housing, and lunch club, for Hammersmith and Fulham residents aged 50+.

105 Greyhound Road, London W6 8NJ

**\** 0207 386 9085

www.ageuk.org.uk



## Agewell courses, Macbeth Adult Education Learning and Skills Centre

Macbeth Centre, Macbeth Street London W6 9JJ

**\** 0208 753 3600

www.hfals.ac.uk

#### Creighton Centre

(previously known as Bishop Creighton House)

Care and repair, specialising in disability adaptations, homeline long-term befriending service for older people, disability outreach, a community centre for education, leisure and cultural activities, falls prevention classes.

380 Lillie Road London SW6 7PH

**\** 0207 385 9689

www.creightonhouse.org

#### Fulham Good Neighbours

Provides support with decorating and DIY in the home, gardening, befriending, social clubs including art, reading and chair based exercise, lunch clubs, Sunday afternoon teas and Silver Pub Clubs.

70 Rosaline Road, London SW6 7QY

0207 385 8850

www.fulhamgoodneighbours.org

#### LBHF Library events

Chess club, English conversation, IT help sessions (one to one and in groups), knitting clubs and reading groups at five local libraries.

≥ libraries@lbhf.gov.uk

If you need a home libary service or befriending service, contact:

**\** 0208 753 3872

★ homelibrayservice@lbhf.gov.uk

#### The Masbro Elders Project

Offers advice and information, a befriending service and a weekly Tea Club.

87 Masbro Road London W14 OLR

0207 605 0800

www.upg.org.uk

#### Open Age

Health, leisure and learning for residents aged 50+.

St Charles Centre for Health & Wellbeing Exmoor Street London W10 6DZ

0204 516 9971

www.openage.org.uk

#### **Support services**

#### Mental Health Single Point of Access

If you need help or are in crisis. The trained mental health advisers can help over the phone or contact other services for you if necessary.

0800 328 4444
 Typetalk: users can call 18001 0800 328 4444

### Psychological therapies

Support with problems like stress, anxiety, depression, feeling low, having trouble sleeping or feeling frightened, is available by self-referral or by visiting your GP who may suggest either:

- NHS Talking Therapies for anxiety and depression
- Specialist Older Adult Mental Health Services (SOAMHS)

#### Richmond Fellowship

Richmond Fellowship is a national mental health charity for all ages, with many community and healthcare partners. They have an office at Richmond Gate Medical Practice. Selfreferrals are encouraged.

- Monday Friday, 9:00am 5:00pm
- **\** 0330 008 3808
- Market Ma

#### Opening Doors London

Offers dementia services for the LGBTQ+ community at their Rainbow Carers Group and Rainbow Memory Cafe.

- **\** 0207 183 6260
- www.openingdoors.lgbt

#### Silver Line helpline

Free telephone service for Older Persons. They offer friendship, conversation and support.

- 34 hour, 365 days a year
- **\** 0800 470 8090



