

Dementia care team

# Information for carers or family members of people living with dementia



Your consultant is:	
This ward is called:	
The ward telephone number is:	
The ward manager's name is:	

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## Introduction

As the carer or family member of a person with dementia, we recognise that you will need support while that person is in hospital. We want to work in partnership with you while you are with us.

This booklet is designed to give you information which will be useful in hospital and also when you go home.

You may be providing unpaid care for a relative, partner or friend who could not manage without your help. In this booklet, the term '**your person**', refers to the person living with dementia who has been admitted to hospital.

## Working in partnership with us

At Imperial College Healthcare NHS Trust we understand the importance of family and carers' involvement in our patients' lives. We want to deliver the best possible patient care and to ensure that this happens, any person with dementia in hospital can have a member of their family or carer with them whenever they want. You do not have to follow visiting times and you can stay with your person if you want (although we would advise against this as it will be exhausting for you).

When you come to the ward, ask the staff to give you a Carer's Passport to wear while you are with us. When you have the passport, this does not mean that you are expected to deliver care to your person, this is still the role of the ward staff, but you can help if you want to.

## Top tips for hospital stays

It is important to remember that most people with dementia will be a bit more confused than usual when they come into hospital because it is a change and they are not well. We know that having support from a familiar person, being stimulated, eating and drinking and moving around will help to reduce this confusion.

## Looking after yourself

First of all, make sure that you look after yourself. Use your carer's passport to visit whenever you want to but give yourself time to rest and recover as well.

Remember to eat and drink enough, it can be hard to organise feeding yourself when you are coming to and from the hospital. If you are finding it difficult, please tell us and we will see what we can do to help you.

## What might help your person to feel more settled while they are in hospital:

- bring in familiar objects (but avoid anything valuable) such as favourite things; photographs are often helpful
- always tell the ward staff something personal about your person, what he/she did for a living or as a hobby – it helps our staff to get to know the person
- complete a 'What Matters to Me' document. You can ask the staff on the ward for one. This will tell our staff all the important non-medical facts that will help them to look after your person well

- bring in something that your person likes to do at home like books, sewing or crosswords
- let us know if your person likes music or films and we can try to provide them in hospital. You can bring in your own CDs or DVDs in for them too
- you are welcome to bring in any favourite drinks or food if your person is allowed to eat. Or tell us what these are and we can try to get them for your person

As soon as you can, encourage your person to move around and do things for him/herself. This will ensure that your person does not lose abilities or skills while in hospital. You can ask the therapists on the ward to help and advise you on this.

## What we will do for your person while they are in our care

While your person is in hospital, we will try to provide additional support to ensure that your person feels secure and recovers as quickly as possible. Here are some of the things we can do with and for your person:

- provide a care plan for the nurses to follow if they are having any difficulties caring for your person
- ensure they have access to a range of activities on the wards from music to touch screen computers and some visits from our resident artists or activity co-ordinator
- check they are eating and drinking enough

- offer snack boxes and an alternative menu available to support people with dementia and a specialist team dedicated to helping people eat
- offer alternative therapies such as massage and aromatherapy to help with distress, anxiety and appetite
- assess and identify pain

If you want advice or help from the hospital's dementia care team please contact us (or ask the ward staff to call us.)



If you want any further information about any aspects of dementia, please get in touch and we can bring you some leaflets

## Useful information for family members / carers

### Carers' assessments

If you regularly provide care for your person, there is a legal obligation to offer you a carer's assessment, which covers your own needs. You can discuss the support you'll need with caring and what would help you to maintain your own health and balance with other aspects of your life, such as work and family.

Social services use the carer's assessment to decide what help to provide along with other assessments. If you need to have an assessment you can ask to see a social worker, either in hospital or when you are at home.

### Carers and family support

Admiral nurses are specialist dementia nurses who give expert practical, clinical and emotional support to families living with dementia. Admiral nurses are available across some, but not all London boroughs, so please contact the Admiral Nursing Direct helpline to see whether you can access an Admiral nurse in your area.

Services Admiral nurses provide range from:

- working with both the person living with dementia and their family
- focusing on the needs of the family, including psychological support and relationship centred work to help them understand



and deal with their feelings and learn different coping strategies

- helping families understand dementia and use a range of specialist clinical interventions that help people live well with the condition, and develop skills to improve communication and maintain relationships
- helping families cope with feelings of loss and bereavement as dementia progresses
- providing advice on referrals to other appropriate services and liaise with other health and social care professionals on behalf of the family

The Admiral nurses helpline is a free and confidential service and it is open seven days a week.

- 09.00 – 17.00 Monday, Tuesday, Friday, Saturday and Sunday
- 09.00 – 21.00 Wednesday, Thursday

Call **0800 888 6678** – you can leave a message if the lines are busy

Email [direct@dementiauk.org](mailto:direct@dementiauk.org)

## What happens if you become ill?

People who care for a person with dementia often worry about what would happen if they became ill, particularly in an emergency. Most local authorities have a carers' emergency card scheme and in the event of your illness, support for the person you care for will be started. Contact details for these are listed by area in the support services section at the back of this guide.

## Breaks from caring

Caring for your person can be a fulfilling experience, but eventually it may become more demanding and coping with the needs of your person and meeting your own needs may be difficult. It is easy to forget about yourself and the activities you enjoy so it is very important that you maintain your own individuality, independence, health and wellbeing. If you have a wider family or social group, you could consider asking one of them to spend some time with your person so that you can have time doing an activity you enjoy, knowing that they are safe and cared for.

## Respite

As a carer, there are different ways you can take a break. The kind of break that will suit you will depend on your own needs and circumstances, as well as those of your person. Some carers may maintain an active social life or attend a weekly social club or activity centre. They may wish to holiday with the person they look after, and some may choose to go away alone. A short break or holiday may not always mean going away, some carers enjoy taking a break at home while the person they look after goes away.

## Legal and financial matters

### Benefits

People with dementia and their carers may be entitled to certain benefits, which should be claimed as they can make a great difference to someone's life.

You and the person you care for may be entitled to the following benefits:

### **Council tax benefit**

Council tax exemption (for people with dementia living alone) or discount (for people living with someone).

### **Carer's allowances**

Are available to help you look after someone with substantial caring needs. You do not have to be related to, or live with, the person you care for. You need to be aged 16 or over and spend at least 35 hours a week caring for your person.

### **Attendance allowance**

This is only applicable if a person is receiving substantial care and aged over 65. It is paid at different rates depending on the level of care that your person requires because of their ill health.

If you would like more information about benefits visit [www.gov.uk/browse/benefits/disability](http://www.gov.uk/browse/benefits/disability) or contact your person's social worker. If your person does not have a nominated social worker, please contact their local social services.

### **Power of attorney**

#### **Lasting power of attorney (LPA)**

You might be asked if your person has an LPA in place when they come to hospital. An LPA enables a trusted person (chosen by your

person) to make decisions regarding their property, affairs and personal welfare.

Personal decisions about care, treatment or where the person should live, can be covered by a personal welfare LPA. LPA covering personal welfare can only be used when the person lacks the ability to make specific welfare decisions for themselves.

**If you already have an LPA please bring it in and show the clinical team.**

If you would like to know more information about who can become an attorney and more information about LPA duties visit:

[www.gov.uk/power-ofattorney/organisations/office-of-the-publicguardian](http://www.gov.uk/power-ofattorney/organisations/office-of-the-publicguardian)

## **The Court of Protection**

If a person does not have power of attorney, the Court of Protection can arrange a deputyship to make decisions on a person's behalf.

This will often be a person's relative. For more information visit:

[www.gov.uk/apply-to-the-court-of-protection](http://www.gov.uk/apply-to-the-court-of-protection)

## **Mental capacity**

Mental capacity refers to the ability to make decisions about things which affect a person's life. This includes all decisions from what to eat for breakfast, whether to take medication or who to appoint as an LPA.

Certain medical conditions such as dementia may at some point, affect your person's ability to make these decisions. In this case, an assessment is completed to determine if your person has the capacity to make a specific decision.

Capacity is assessed on a case-by-case basis for example if your person may have capacity to decide what they eat, but not the capacity to decide who manages their financial affairs. Mental capacity is often assessed in hospital settings when an important decision needs to be made.

## Support services

### National support

#### Age UK

A UK-wide charity which can provide information and advice, subsidised holidays, insurance, legal and financial advice and wills, day care, carers groups, and community dementia support workers.

Call **0800 678 1602**

Visit [www.ageuk.org.uk](http://www.ageuk.org.uk) for more information about local services

#### Alzheimer's Society

A national charity providing support to people with all types of dementia and their carers. The society provides: a helpline, day care, support services, carers groups, social events, advice and help with claiming benefits and a monthly newsletter with articles about research and tips from other carers.

Call **0333 150 3456** for details of your local branch. Visit

[www.alzheimers.org.uk](http://www.alzheimers.org.uk)

## **Dementia UK Helpline**

The helpline is available from 09:15 - 16:45pm Monday to Friday and 18.00 to 21.00 on Wednesdays and Thursday evenings.

Or email [direct@dementiauk.org](mailto:direct@dementiauk.org)

Call **0800 888 6678**

Visit [www.dementiauk.org](http://www.dementiauk.org)

## **Carers Trust**

This is a charity which supports unpaid carers through: short breaks, information, advice, education, training and employment opportunities, emotional and practical help. They have a network of 116 independent carers centres, 55 Crossroads Care schemes which provide care in people's home so carers can take a break and 99 young carers services.

Call **0300 772 9600**

Visit [www.carers.org](http://www.carers.org)

## **Carers UK**

This charity offers expert advice, information and support for all carers. Including a useful hand out *Your guide to a Carer's Assessment* and a telephone advice and support service, called The Carers UK Advice line.

Call **0808 808 7777** from 10.00 - 16.00 - Monday to Friday Visit

[www.carersuk.org](http://www.carersuk.org)

## **Cinnamon Trust**

A charity that helps older people to be with their pets for longer, including dog walking and long-term accommodation for owners who have died or moved into residential care.

09.00 – 17.00 Monday to Friday

Call **01736 757900**

Visit: [www.cinnamon.org.uk](http://www.cinnamon.org.uk)

## Holidays

### **The Mede**

The Mede is a company that has three bungalows offering short breaks and day care for people with dementia and their carers.

Call **01392 421189**

Visit [www.themedede.org](http://www.themedede.org)

### **Revitalise**

Revitalise is a charity that provides short breaks and holidays for people with physical disabilities and carers. Call **0303 303 0145**

Visit [www.revitalise.org.uk](http://www.revitalise.org.uk)

### **Dementia Adventures**

A social enterprise which runs small group short breaks and holidays for people living with dementia and their carers. They offer an alternative to traditional respite as their short breaks mean people living with dementia can get outdoors, connect with nature and retain a sense of adventure in their lives.

Open for enquires between 09.00 – 17.00 Monday to Friday

Call **01245 373397**

Visit [www.dementiaadventure.co.uk](http://www.dementiaadventure.co.uk)

## Local support services

### **Brent**

#### **Age UK, Brent**

Age Concern Brent offers a range of services and projects to support, inform, advise and inspire older people. The service assists with one-off queries and extended support for more complex issues. They offer

an advocacy and befriending service and a service to encourage healthy eating.

120 Craven Park Road, Harlesden, NW10 8QD

Call **020 8756 3040 (09am-3pm)**

Visit [www.ageukbrent.org.uk](http://www.ageukbrent.org.uk)

### **Asian People's Disability Alliance (APDA)**

The service is for Asian elderly and disabled people and their carers and families. The service provides advice and information, peer counselling, volunteer support and day care services.

APDA (Asian People's Disability Alliance) Day Care and Development Centre,

Alric Avenue (off Bruce Road), London. NW10 8RA

Call **020 8459 1030**

Visit [www.apda.org.uk](http://www.apda.org.uk)

### **Alzheimer's Society, Brent**

Templeton Centre, Joel Street, Northwood Hills Middlesex, HA6 1NL

Call **01923 823999**

Visit [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

### **Brent Carers Centre**

Willesden Medical Centre, 3rd Floor, 144-150 High Road, Willesden London, NW10 2PT

Monday to Friday: 09.00 – 17.30

Third Wednesday of the month open until 20.00

Last Saturday of the month 10.00 – 13.00

Call **020 3802 7070**

### **Hammersmith and Fulham**

**Age UK, Hammersmith and Fulham**



A community resource with garden, open Monday to Friday from 10.00 – 16.00. Services on offer range from lunches, talks, bingo, films, advice and information, exercise classes, computer classes, crafts, therapy room to a lending library. There are also befriending and shopping services. Age UK has a free newspaper which is available at Hammersmith and Fulham Town Hall, newsagents and libraries.

105 Greyhound Rd, London W6 8NJ

Call **020 7386 9085**

Visit [www.ageuk.org.uk/hammersmithandfulham](http://www.ageuk.org.uk/hammersmithandfulham)

### **Alzheimer's Society, Hammersmith and Fulham**

They provide a support group for people living with the early stages of dementia, day support services, dementia support services , newsletters, Saturday café, and 'Singing for the brain' music therapy and singing service.

St Vincent's, 49 Queen Caroline Street, Hammersmith, London W6 9QH Call **020 8563 0001**

### **Carer's emergency card**

Call **020 7386 9417**

Visit [www.carers-network.co.uk](http://www.carers-network.co.uk) to download an application form

### **Elgin Close resource centre**

A local community resource that provides a range of free and paid activities and support in a safe and comfortable environment. This information, advice and signposting service includes workshops, activities, IT facilities, space to read and a daily lunch club. There is a dedicated outreach worker, drop-in service and a floating support service for older persons at home.

Address: 1-3 Elgin Close (off Goldhawk Rd), Shepherds Bush, London W12 9NH

Call **020 8762 3007**

Visit [www.nottinghillhousing.org.uk](http://www.nottinghillhousing.org.uk)

### **Hammersmith and Fulham Family Support Service**

This helpline is the first point of contact if you need any information or advice about being a carer.

Open Monday to Friday, 08am – 6pm

Call freephone **0800 996 1754** from a landline or **0800 145 6095**

### **Imperial Wharf Resource Centre**

Imperial Wharf Resource Centre aims to support adults to remain in their own homes. The centre provides a safe environment for service users to socialise, enjoy a nutritious meal and take part in a range of activities. The centre offers day time respite for carers and is open seven days a week. They provide therapeutic exercise groups, enhance key skills and provide meals. Imperial Wharf Resource Centre, Olive House, 185 Townmead Road, London SW6 2JY

Call **020 7384 6950**

### **Shanti Centre via the Asian Health Agency**

Shanti provides a range of individually tailored and culturally appropriate services including, day care for older people, people with disabilities, people with substantial health needs and debilitating conditions, and respite care services which includes carers. There is also a lunch service and takeaway which caters for both vegetarians and non-vegetarians, including halal meals available daily between 12.00 noon to 14.00.

Further services include health education and health promotion activity. Referrals are by a GP or health professional, social services or self-referral.

89 Askew Road, London, W12 9AS

Call **020 8811 1501**

Visit [www.taha.org.uk](http://www.taha.org.uk)

## **Kensington and Chelsea**

### **Age UK Kensington and Chelsea**

Supports people living with dementia or memory difficulties and their friends and family, both in groups and one-to-one. The charity also offers education sessions on memory management and dementia for those wanting to know more.

**Sessions include:** Ageing well

My memories café

Trips and outings

Men's groups and activities

Young at heart

Exercise for the mind

One to one support

Dementia support

Dementia advisor

Call **020 3181 0002** - ask for the health and wellbeing team or email

[dementia@aukc.org.uk](mailto:dementia@aukc.org.uk)

09.30am – 17.30 Monday to Friday, please note the centre is closed between

13.00 – 14.00

1 Thorpe Close, London W10 5XL

Call **020 8969 9105**

### **Carer's emergency card**

Call **020 7605 6509**

Email [tcommunityalarmservice@kctmo.org.uk](mailto:tcommunityalarmservice@kctmo.org.uk)

## Carers Kensington & Chelsea

Carers Kensington and Chelsea, provides information, advice and support for unpaid carers who are finding it difficult to manage on their own. Contact for advice on the following: benefits and grants for carers and people they look after community care assessments, carer's assessments and how to get support from the Council, carer personal budgets, local services available for carers including health, support, activities, outings and counselling how to get support for the person with care needs.

Carers Kensington and Chelsea also offer home visits to carers who have mobility problems or to those who cannot leave the person they care for home alone.

Call **0800 032 1089** free phone from landlines to book an appointment

## Open Age

Open Age is a user led charity working across the Royal Borough of Kensington and Chelsea and Westminster to enable older people to sustain their physical and mental fitness, maintain active lifestyles and develop new and stimulating interests.

The charity provides a wide range of physical, creative and mentally stimulating activities to enable older people to develop new skills, fulfil their potential, and encourage social interaction, thus helping reduce loneliness, isolation and depression. Open Monday to Friday 09.00 – 17.00

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

Call - **020 8962 4141**

Email [mail@openage.org.uk](mailto:mail@openage.org.uk)

## Westminster

### Age UK, Westminster

Age Concern Westminster offers specialist advice and home support services for older people including befriending.

Enquiries in person Monday – Friday 10.00 -12.00 noon **Call 0800 169 6565** - Age UK advice national helpline

Visit [www.acwestminster.org.uk](http://www.acwestminster.org.uk)

### Carer's Network, Westminster

Is a locally based charity in Westminster providing support, information, breaks and grants for unpaid carers.

Call **020 8960 3033**

Visit [www.carers-network.co.uk](http://www.carers-network.co.uk)

### Carer's emergency card

[Visit www.westminster.gov.uk/care-support-group to apply](http://www.westminster.gov.uk/care-support-group)

### Dementia Advisor

Westminster dementia adviser service

42 Westbourne Park Road, London, W2

5PH Call **07540 502379**

Email [terezie.holmerova@housingandcare21](mailto:terezie.holmerova@housingandcare21).

### Memory café

Group based support for people with dementia, their families and supporters with varied activities. Café sessions provide a warm and friendly environment as well as information from local health and carer related services.

North Westminster Memory café, 42 Westbourne Park Road, London, W2 5PH. Call **020 3317 3666**

South Westminster Memory café, Victoria Medical Centre, 29 Upper  
Tachbrook Street, London SW1V 1SN. Call **0370 192 4265**

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