

Information for patients with dementia and their carers



Hillingdon Hospital NHS Trust is committed to both improving the level of support and the hospital experience of patients with dementia and their carers

This leaflet provides a general overview about dementia, a description of Hillingdon Hospital's Forget-Me-Not Scheme, hospital tips for carers, and useful contact number for additional information and support outside of the hospital.

What is dementia?

The term 'dementia' describes a set of symptoms which include loss of memory, mood changes, and problems with communication and reasoning. These symptoms occur when the brain is damaged by certain diseases, including Alzheimer's disease and damage caused by a series of small strokes (vascular dementia).

Dementia is progressive, which means the symptoms will gradually get worse. How fast dementia progresses will depend on the individual person and what type of dementia they have. Each person is unique and will experience dementia in his/her own way. Often, the person's family and friends are more concerned about the symptoms than the person may be themselves.

Symptoms of dementia may include the following:

- Loss of memory – particularly short-term memory, for example forgetting what happened earlier in the day, not being able to recall conversations, being repetitive, or forgetting the way home from the shops. Long-term memory is usually still quite good.
- Mood changes – people with dementia may be withdrawn, sad, frightened or angry about what is happening to them.
- Communication problems – including problems finding the right words for things, for example being able to describe the function of an item instead of naming it.

In later stages of dementia, the person affected will have problems carrying out everyday tasks and will become increasingly dependent on other people.

Adapted from the Alzheimer's Society 2013 Factsheets

What causes dementia?

There are several diseases and conditions that result in dementia:

- Alzheimer's disease – This is the most common cause of dementia. During the course of the disease the chemistry and structure of the brain changes, leading to the death of brain cells. Problems of short-term memory are usually the first noticeable sign.
- Vascular dementia – If the oxygen supply to the brain fails due to vascular disease, brain cells are likely to die and this can cause the symptoms of vascular dementia. These symptoms can occur either suddenly, after a stroke, or over time through a series of small strokes.
- Dementia with Lewy bodies – This form of dementia gets its name from tiny abnormal structures that develop inside nerve cells. Their presence in the brain leads to the degeneration of brain tissue. Symptoms can include disorientation and hallucinations, as well as problems with planning, reasoning, and problem solving. Memory may be affected to a lesser degree. This form of dementia shares some characteristics with Parkinson's disease.
- Fronto-temporal dementia (including Pick's disease) – damage is usually focused in the front part of the brain. At first, personality and behaviour changes are the most obvious signs.
- There are many other conditions which may cause dementia.

Diagnosing dementia

It is very important to get a proper diagnosis. It is possible to be prescribed treatment for Alzheimer's disease. Whether you are someone with dementia or a carer, a diagnosis can help with preparing and planning for the future.

Dementia can be diagnosed by a doctor, who should rule out any illnesses that might have similar symptoms to dementia, including depression. The doctor may carry out a number of tests to check basic thinking processes and the ability to perform daily tasks. They may request further tests, such as a brain scan or a more in-depth assessment of memory, concentration and thinking skills.

Adapted from the Alzheimer's Society 2013 Factsheets

Hillingdon Hospital's Forget Me Not Scheme

The Forget Me Not Scheme makes sure that hospital staff recognises each person with known or suspected dementia so that they can provide special care. Components of the scheme are summarized briefly below.

Forget-Me-Not visual alert magnet

Patients with known or suspected dementia will have a forget-me-not visual alert symbol beside their name on the electronic whiteboard and above their bed (with the consent of the patient or carer) This highlights to staff that these patients are likely to require special care planned around the patients unique needs

This Is Me (Alzheimer's Society):

This leaflet summarizes information about each patient, such as his/her likes and dislikes, so that staff can provide effective care adapted to each patient's unique needs. A member of staff will fill out this form with the patient and his/her carer or relative. With permission, staff who will refer to the information to guide how they provide care. We recommend that each person with dementia fills in this leaflet with assistance from a carer or relative. The leaflet also contains information about the person's life including hobbies, and a biography. Please do keep the original document safe and make a copy to give to staff whenever you need to come to hospital.

The Carer's Guide and Passport:

The Hillingdon Hospitals NHS Foundation Trust greatly values the support of family and friends caring for people who use our services and we recognise carers as expert partners in care. In the best interest of the patient, we welcome carers staying with the person they support outside of normal visiting hours, should they and the patient so wish. Our Carers Guide has been developed to provide information about how we can work together with carers to help make this as easy as possible. Following a discussion we will issue a Carers

Passport/Badge to all carers who wish to be more involved in care whilst the patient is in hospital, the badge helps staff to identify you as a carer and plan how they work with you.

Carer's Survey:

We collect feedback from patients and carers using this questionnaire.

We greatly value all comments and will use them to strive to improve the experience of our patients and their carers. Please fill in a survey and return it to the ward receptionist or member of staff.

Other – Medical Checklist:

A doctor will use this detailed list to ensure that all aspects of medical care are checked daily.

Hospital Tips for Carers:

- **Use your Carer's Passport** to visit the patient in hospital and provide support any time. Your personal knowledge and experience with the patient is extremely valuable to the whole team.
- **Complete This is Me** with a member of staff.
- Ensure the patient has their **dentures, glasses, and hearing aids** available and in use as much as possible while in the hospital.
- **Personalise the patient's environment.** Familiar items such as photo albums, a favourite stuffed animal, a blanket from home, or activity they enjoy can alleviate anxiety commonly experienced in the unfamiliar hospital environment. Please consult staff first about items you wish to bring in.
- **Notify staff if you notice a change in the patient's usual behaviour.** For example, notify staff if the patient is not alert as usual, or displays behaviour that is not typical of the way they normally behave at home (e.g. hallucinating), or a mix of both.
- **Get connected** with your community for additional dementia information and support (see First Contact number below).

Who to contact

Hillingdon Alzheimer's Society

01923 842444 Julia James: 07803115535

Email

HarrowandHillingdon@alzheimers.org.uk

Hillingdon Carers

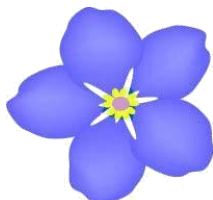
01895 811206

office@hillingdoncarers.org.uk

www.hillingdoncarers.org.uk

Antonia Samargiu, Dementia Clinical Nurse Specialist, Hillingdon Hospital

01895 279 782



DEMENTIA CARER SURVEY

Month of admission:

Current ward:

| | | | |
|--|-------------------------------------|---|-------------------------------------|
| 1. As the carer for the person with dementia, on their admission to hospital, were you asked about: | | | |
| • Their usual routines | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Don't know <input type="checkbox"/> |
| • What's important to them | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Don't know <input type="checkbox"/> |
| • What makes them feel better when they get anxious or upset | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Don't know <input type="checkbox"/> |
| 2. Were you asked about the extent to which you would like to be involved in the care of the person with dementia whilst they were in hospital? | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Don't know <input type="checkbox"/> |
| 3. Did you feel you were able to visit at appropriate times to support the care of the person with dementia? | Yes always <input type="checkbox"/> | Yes, sometimes <input type="checkbox"/> | No <input type="checkbox"/> |
| 4. As the carer of the person with dementia, were you involved as much as you wanted in the decisions about their care and treatment? | Yes always <input type="checkbox"/> | Yes, sometimes <input type="checkbox"/> | No <input type="checkbox"/> |
| 5. Did the hospital provide you with information on dementia and the support services available to you? | Yes <input type="checkbox"/> | No <input type="checkbox"/> | |
| 6. Do you feel there is adequate support for carers of people with dementia outside of hospital? | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Don't know <input type="checkbox"/> |
| 9. What else could be done to improve support for those who care for someone with dementia? | | | |
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The Hillingdon Admiral Nurse Team

Are you caring for a Person with Dementia?
(or very likely to have dementia?)

**Would you like to attend a
Carers Information Day?**

**If you would like to attend please complete the referral form over
leaf and post the form back to:**

The Hillingdon Admiral Nurse Team
3W/11 Civic Centre
Uxbridge
Middlesex
UB8 1UW
Telephone - **01895 556480**

**If you require any further information about the next Hillingdon Admiral
Nurse Carers Information Day please contact the Admiral Nurses on
01895 556480. You will be sent full details of the event nearer the time.**

Unfortunately we are unable to provide any respite on the day for the
person you care for, and you will need to make your own arrangements.

Trust Headquarters, Stephenson House, 75 Hampstead Road, London NW1 2PL

Telephone: 020 3214 5700

www.cnwl.nhs.uk



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Admiral Nurse Carers Information Day

Your Details

Title:

Name:

Marital Status:

Address:

Your GP Name & Address:

Employment Status:

Telephone contact details:

E-mail address:

Date of Birth:

Male/Female

(delete as appropriate)

Country of Birth:

Ethnic Background:

Religion:

Relationship to Person with Dementia:

How/where did you find out about the Carers Information Day?

Do you have any special requirements for the day?

(please call if you need to discuss your needs further)

Person with Dementia's Details

Title:

Name:

Marital Status:

Address: (if different from yours)

G.P Name & Address:

Diagnosis & Date of Diagnosis (if known)

Date of Birth:

Religion:

Country of Birth:

Ethnic Background:

Trust Headquarters, Stephenson House, 75 Hampstead Road, London NW1 2PL

Telephone: 020 3214 5700

www.cnwl.nhs.uk



Wellbeing for life

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Dementia groups

Our dementia groups are for residents and their carers who are in the early to mid-stages of dementia. The sessions offer a social opportunity for residents to meet others also living with dementia, plus a range of activities including reminisce, chair exercise, such as Boccia, bingo, art, music and much more. Please note: Booking is essential.

| Location | Date | Times |
|-------------------------|-----------|-------------------------------------|
| Botwell Library | Thursday | 11am to midday |
| Harefield Library | Wednesday | 2.30pm to 3.30pm |
| Ruislip Manor Library | Wednesday | 2.30pm to 3.30pm |
| Northwood Hills library | Tuesday | 2.30pm to 3.30pm |
| Oak Farm Library | Thursday | 2pm to 3pm |
| Uxbridge Library | Tuesday | 10am to 11am and 11.30am to 12.30pm |
| West Drayton library | Thursday | 2pm to 3pm |
| Yeading Library | Tuesday | 2pm to 3pm |

To book or for more information about our dementia groups, please email sdurner@hillingdon.gov.uk or call 01895 277137.

Early onset dementia groups

Our early onset dementia groups are aimed at residents living with dementia and carers under the age of 65 years. Sessions offer an opportunity to meet others of a similar age also living with dementia, plus a range of activities including reminiscence, art and chair-based exercises.

| Location | Day | Time(s) |
|-------------------|-----------|--------------|
| Botwell Library | Thursdays | 4pm to 5pm |
| Northwood Library | Thursdays | 10am to 11am |

To book or for more information about our early onset dementia groups, please email sdurner@hillington.gov.uk or call 01895 277137.

Activities for people living with dementia

The following activities allow residents living with dementia and their carers to continue to engage with everyday activities, such as leisure, theatre and technology.

These activities will be updated/added to regularly.

| Group name | Location(s) | Day | Time(s) |
|-----------------------------------|--------------------------|----------|----------------|
| Adapted golf sessions | West Ruislip Golf Centre | Mondays | 10am to midday |
| Reminiscence session | Online (via Zoom) | Mondays | 2pm to 2.40pm |
| Early onset walking tennis | Uxbridge Sports Club | Tuesdays | 1pm to 2pm |
| Forget Me Not FC walking football | Rectory Park | Fridays | 11am |

To book onto one of these activities, email sdurner@hillington.gov.uk
call 01895 277137.

Monthly daytime discos

Programmed for those living with dementia to enjoy and reminisce, these new monthly Daytime Discos at the Compass Theatre, Ickenham feature popular music from the 50s, 60s, 70s and 80s with space to dance or just listen.

For more information or to book, visit the [Compass Theatre's website](#).

Visitors' Parking Permit Authorisation

Date: _____

Ward: _____

Please issue a permit to:

Visitors' Name: _____

Patients Name: _____

Car Registration: _____

For: 1 Week/ 1 Month (Please circle one)

FEE: 1 Week = £12.00 (Please circle one)

1 Month = £25.00

This charge is for one vehicle.

Signed by Ward Manager/Nurse in Charge

THIS FORM IS NOT VALID WITHOUT AN

OFFICIAL SIGNATURE

Please take this form to the security office