Information for patients with dementia and their carers
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- Mood changes – people with dementia may be withdrawn, sad, frightened or angry about what is happening to them.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 recognise 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 patient’s 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 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 Carer’s 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 a plan on 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 823 999
Email: harrowandhillingdon@alzheimers.co.uk

**Hillingdon Carers**
01895 811206
office@hillingdoncarers.org.uk
www.hillingdoncarers.org.uk

**Lorna Kelly, Dementia Clinical Nurse Specialist, Hillingdon Hospital**
01895 279 782
**DEMENTIA CARER SURVEY**

Month of admission:

Current ward:

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. As the carer for the person with dementia, on their admission to hospital, were you asked about:</td>
<td></td>
<td></td>
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<tr>
<td>- Their usual routines</td>
<td>Yes</td>
<td>No</td>
<td>Don’t know</td>
</tr>
<tr>
<td>- What’s important to them</td>
<td>Yes</td>
<td>No</td>
<td>Don’t know</td>
</tr>
<tr>
<td>- What makes them feel better when they get anxious or upset</td>
<td>Yes</td>
<td>No</td>
<td>Don’t know</td>
</tr>
<tr>
<td>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?</td>
<td>Yes</td>
<td>No</td>
<td>Don’t know</td>
</tr>
<tr>
<td>3. Did you feel you were able to visit at appropriate times to support the care of the person with dementia?</td>
<td>Yes always</td>
<td>Yes, sometimes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No</td>
<td></td>
<td></td>
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<tr>
<td>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?</td>
<td>Yes always</td>
<td>Yes, sometimes</td>
<td></td>
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<td></td>
<td>No</td>
<td></td>
<td></td>
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<tr>
<td>5. Did the hospital provide you with information on dementia and the support services available to you?</td>
<td>Yes</td>
<td>No</td>
<td></td>
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<tr>
<td>6. Do you feel there is adequate support for carers of people with dementia outside of hospital?</td>
<td>Yes</td>
<td>No</td>
<td>Don’t know</td>
</tr>
<tr>
<td>9. What else could be done to improve support for those who care for someone with dementia?</td>
<td></td>
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Please continue overleaf if necessary.
Languages/ Alternative Formats

Please ask if you require this information in other languages, large print or audio format.

Please contact: 01895 279973

Fadlan waydii haddii aad warbixintan ku rabto luqad ama hab kale. Fadlan la xidhiidh 01895 279 973

If you require this information in other languages, large print or audio format, please contact the Patient Information Department by telephone at 01895 279973.

Jeżeli chciałbyś uzyskać te informacje w innym języku, w dużej czcionce lub w formacie audio, poproś pracownika oddziału o kontakt z biurem informacji pacjenta (patient information) pod numerem telefonu: 01895 279973.

如果你需要這些資料的其他語言版本、大字体、或音頻格式，請致電 01895 279973 查詢。

إذا كنت تود الحصول على هذه المعلومات بلغة أخرى، بالأحرف الكبيرة أو بشكل شريط صوتي، يرجى الاتصال بالرقم التالي: 01895279973.