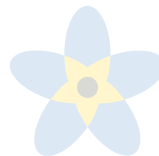
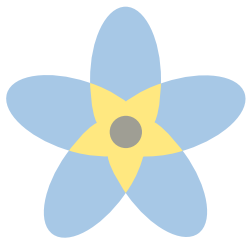
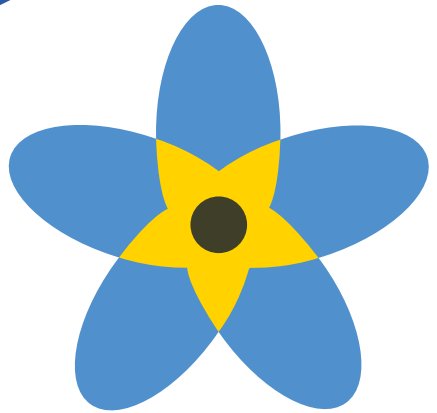


Dementia

Information for patients and carers



The Leeds Teaching Hospitals 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 how Leeds Teaching Hospitals uses Forget-Me-Nots, hospital tips for carers, useful contact numbers for additional information and support outside of the hospital, carer's survey.

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.
- **Concentrating, planning or organising** – for example difficulties making decisions , problem solving or carrying out a sequence of tasks like cooking a meal.
- **Mood changes** – people with dementia may be withdrawn, sad, frightened or angry about what is happening to them.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. There may also be difficulties following conversations.

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 abnormal protein surrounding brain cells and another protein damages their internal structure. Chemical connections between brain cells and cells begin to die. Other signs may include difficulties finding the right words, solving problems and making decisions.
- **Vascular dementia** – If the oxygen supply to the brain is reduced due to narrowing or blockages of blood vessels some brain cells become damaged or 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. Symptoms may vary but can overlap with Alzheimer's disease. People may have difficulty with problem-solving, planning, thinking quickly and concentrating.
- **Mixed Dementia** – This is when someone has more than one type and a mixture of symptoms. It is common for someone to have both Alzheimer's and Vascular dementia together.
- **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 disrupts the chemistry and leads to the death of brain cells. 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.

- **Frontal-temporal dementia (including Pick's disease)** – In this dementia damage is usually focused in the front part of the brain caused by abnormal proteins forming inside brain cells, causing them to die. At first, personality and behaviour changes are the most obvious signs.

There are many other conditions which may cause dementia.

In later stages of dementia, the person affected will have problems carrying out everyday tasks and will become increasingly dependent on other people. However, many people live well with dementia following their diagnosis. For more information about dementia look at the Alzheimer's Society Website.

Diagnosing dementia

It is very important to get a proper diagnosis. It is possible to be prescribed medication to slow down or help with symptoms e.g in 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 and delirium (or not their usual self), when a person can become confused during an episode of ill health. 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.

Forget-Me-Not Scheme

The Forget-Me-Not Scheme makes sure that hospital staff are able to 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

People with known or suspected dementia will have a forget-me-not visual alert symbol on the name board at the end of the bed or behind the head board (with the consent of the person or carer when possible). This highlights to staff that these people are likely to require special care planned around the persons unique needs.

This Is Me (Alzheimer's Society)

This leaflet summarizes information about each person, such as his/her likes and dislikes, so that staff can provide effective care adapted to each persons unique needs. If not already completed before admission a member of staff will provide a form to be filled in by the person 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.

Johns Campaign

Leeds Teaching Hospital NHS Trust is signed up to John's campaign which asks for families and carers of patients to be invited to stay with them in hospital for as many hours as needed and they are able to give. Please discuss with the Nurse In Charge.

Carers

The Leeds Teaching Hospital NHS 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. Please discuss with the nurse in charge and ask if the Carers passport is available rolling out in a staged approach across the Trust.

If you are a carer that works for Leeds Teaching Hospitals NHS Trust talk to your manager about your caring responsibility and complete the Employee Carer Passport. Also visit the Staff Health and Wellbeing internet page at: <https://www.leadsth.nhs.uk/staffhealthandwellbeingsupportnetwork/carers-support/>

Carer's Survey

We collect feedback from patients and carers using a 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 found at the back of the leaflet and return it to the ward receptionist or member of staff. There is also an online version.

Hospital Tips for Carers

Let the team know if you wish to help care and support the person with dementia. Your personal knowledge and experience of the person is extremely valuable to the whole team.

- Complete a **This is Me** and let the staff have a copy.
- Ensure the person has their dentures, glasses, and hearing aids available and in use as much as possible while in the hospital. It is helpful for these to be marked with the persons name.
- If the person has not brought a list of medications with them on admission please let staff know what the medications are. It is also useful for us to know if someone helps the person to take their medications or does it for them who that person is and how we would contact them.
- Personalise the person'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 person's usual behaviour. For example, notify staff if the person 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.
- Notify Staff if you think the person would prefer a finger food menu choice.
- Get connected with your community for additional dementia information and support.
- Please bring in comfortable, easy to put on clothes for the person and good fitting footwear to help us keep the person as active as possible.
- If you are worried about anything please speak to the Nurse In Charge.

Who to Contact

Hospital Dementia Carer Support Workers from Carers Leeds

Tel: 0785 448 1024

Who offer a wide range of information, advice and support for Carers.

Carers Leeds

Tel: 0113 380 4300 **Email:** info@carersleeds.org.uk

Address: 6-8 The Headrow, Leeds, LS2 6PT

Website: www.carersleeds.org.uk

Patient Advisory Liaison Service (PALS)

Tel: 0113 206 7168 / 0113 222 4401

Email: patient.relations@leedsth.nhs.uk

Adult Social Care

Tel: 0113 222 4401

Age UK

Tel: 0113 389 3000

Age UK has an office in Leeds and provides a range of advice and services including on money matters.

The Alzheimer's Society

Memory Support Worker Service

This service works across Leeds with people who have dementia, you can contact the team for advice about living with dementia and what practical, emotional and other help is available local to you. The service works in a joined-up way with the NHS and social care in Leeds.

Tel: 0113 231 1727 **Email:** memorysupport.lypft@nhs.net

Dementia UK

Helpline: 0800 888 6678

Leeds Directory

Website: www.leedsdirectory.org

Care & Repair

Website: www.care-repair-leeds.org.uk

Chaplaincy

St James's Tel: 0113 206 5935 **LGI Tel:** 0113 392 2914

In office hours or in an emergency via Switchboard, available 24 hours a day.

If you care for someone with dementia and worry they might go missing look at the Herbert Protocol

Website: www.westyorkshirepoliceuk/dementia

Notes:

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Acknowledgements:

- Alzheimer's Society online factsheets 2017
- Hillingdon Hospitals Foundation NHS Trust
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Local Services Manager (Leeds and Kirklees) West Yorkshire



What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter



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Dementia Carers' Survey

Leeds Teaching Hospitals want to ensure that carers of people with dementia and other memory problems feel well supported. We would greatly value feedback on the service we provide carers and would appreciate it if you could take a few minutes of your time to complete either our online survey, this can be completed online at <https://www.leedsth.nhs.uk/dementia-carers-survey> or this paper document on the back of this leaflet which can be torn off and handed to the ward clerk at discharge. Please tick the box for your answers.

Which hospital was the person you care for in?

St James's Hospital Leeds General Infirmary Other

Which ward were they on?

Month of admission:

1. 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 No Don't Know

2. Were you (or the person with dementia, where appropriate) involved as much as you wanted to be in decisions about their care and treatment including discharge?

Yes No Don't Know

3. Did hospital staff ask you about the needs of the person you look after to help plan their care?

Yes No Don't Know

4. Did you feel you were able to visit at appropriate times to support the care of the person with dementia?

Yes always Yes sometimes No

5. When the person you care for was in hospital how often did staff ask whether you were having difficulties or problems with caring?

Not at all Not Often Quite often Often

6. Did staff give you information about agencies in Leeds which might be able to help and support you as a carer?

Yes No

7. If you were given information, how useful was it?

No use at all Not much use Quite useful Very useful

8. What else could be done to improve support for those who care for someone with dementia?

We take your feedback very seriously. Thank you

Please give to the ward clerk for attention of Lead Nurse
Rosemary Horsman care of Patient Experience Trust HQ.

