

Living with dementia - supporting you during a hospital stay

Patient Experience Team

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Information for Patients, Families and Carers

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Introduction

This leaflet has been produced with support from Age UK Leicestershire and Rutland for people living with dementia and their carers.

We hope this will help you understand more about dementia as well as providing some useful information to ensure you, or your relative's stay in hospital is as comfortable as possible.

What is dementia?

The term 'dementia' describes a set of symptoms which includes 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 when damage is caused by a series of small strokes.

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 their own way.

Types of dementia

There are many different types of dementia and there are several different diseases and conditions that result in dementia. Some of these include:

- **Alzheimer's disease** - this is the most common cause of dementia. During the course of this disease the chemistry and structure of the brain change, leading to the death of brain cells. Problems in short-term memory are usually the first noticeable sign.

**Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice**

Visit www.leicestershospitals.nhs.uk for maps and information about visiting Leicester's Hospitals
To give feedback about this information sheet, contact InformationForPatients@uhl-tr.nhs.uk

- **Vascular dementia** - this type of dementia is caused by reduced blood supply to the brain due to diseased blood vessels. 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.
- **Fronto-temporal dementia (including Pick's disease)** - in fronto-temporal dementia, damage is usually focused in the front part of the brain. Personality and behaviour changes are the most obvious signs.
- **Dementia with Lewy bodies** - this form of dementia gets its name from tiny abnormal structures that develop inside nerve cells. Their presence leads to the damage 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.

How can I tell if I have dementia?

Many people fear they have dementia, particularly if they think their memory is getting worse or if they have known someone who has had the illness. Becoming forgetful does not necessarily mean that you have dementia.

If you are concerned, please see your doctor.

How is dementia diagnosed?

It is very important to get a dementia diagnosed correctly. A diagnosis will help the doctor rule out any illnesses that might have similar symptoms, including depression. Having a diagnosis of dementia may also mean it is possible to be prescribed medication in certain cases.

Dementia can be diagnosed by a specialist. This may be a doctor who specialises in the care of older people (a geriatrician), someone who specialises on diseases of the nervous system (a neurologist), or a mental health specialist (a psychiatrist). 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. In hospital, if a patient has a history or sudden decline in their memory, we carry out blood tests to rule out any other reasons of why this has happened.

Can dementia be prevented?

At present, it is not clear what causes most of the diseases that lead to dementia, or what can be done to prevent dementia itself.

Evidence does suggest that a healthy diet and lifestyle may help protect against dementia. In particular, exercising regularly, avoiding fatty foods, not smoking, alcohol in moderation and keeping mentally and socially active as you age, may help to reduce the risks.

Can dementia be cured?

Unfortunately, there is no known cure, although improvements in management of the symptoms continue. Drugs have been developed to temporarily help with some of the symptoms of some types of dementia, mainly Alzheimer's disease. There are also treatments to reduce the risk of stroke in vascular dementia.

Care during a hospital stay

Hospital environments can be extremely disorientating and sometimes can cause increased agitation for the person living with dementia. However, there is a lot that can be done to help people adapt to the new environment.

Staff are happy to answer any questions and discuss any issues you may have. If at times they seem too busy to talk, please do ask to make an appointment, ideally with the nurse or doctor caring for you or the person you care for.

Important! If you notice the person you care for is more confused or withdrawn than usual please tell the nurse or doctor. This may be related to a progression in dementia but it could also mean an underlying medical problem we may be able to treat. This medical problem is often described as 'delirium'. If you would like further information about delirium, please ask a member of staff for the 'understanding delirium' leaflet.

How people cope with dementia will be unique and individual to each person. It is really important that staff are aware of how dementia affects a person and in particular how their behaviour may indicate certain issues, such as being in pain, needing a drink or tiredness.

Familiar things, such as photographs of family members or a much-loved pet on the bedside table, can be very reassuring for a person with dementia in an unfamiliar environment. Own clothes can also help the person feel more secure and safe.

Please avoid bringing valuable items or irreplaceable photographs into hospital, as occasionally items can get lost or become misplaced.

'Know Me Better' patient summary - information in hospital may seem to focus on the medical needs of the person. It is really useful for a family member, carer or friend to ensure that other important information about the person with dementia is also provided.

Whilst in hospital please ask a member of staff for a 'Know Me Better' Patient Summary so you can tell us more about the person living with dementia.

'What Matters To Me' sign - different things matter to different people when they are admitted to hospital. To help us understand what matters the most to the person living with dementia, we can place a simple sign above the bed to remind all staff of what this is so the person feels supported.

Eating and drinking - we know that some people with dementia may need extra support at mealtimes. You can get involved by assisting at mealtimes if you think this may help. Other ways in which we can help are:

- mealtime volunteers, who have been specifically trained to help people who need assistance with their food and drink, are available.
- providing specially adapted cutlery and crockery to promote independence.
- offering smaller size (calorie dense) meals if the standard size meals are too large.
- providing additional snack foods for those who prefer to graze day and night, or need additional calories.
- promoting 'enhanced mealtimes' where patients shall not be disturbed so they can enjoy their meals without interruption.
- offering a quieter place to eat that creates a more sociable environment.
- the availability of different menus so patients are given a choice, including braille and picture menu.
- providing red trays so that patients who need additional support can be identified.
- use the weekly meal planner so that family and carers can help to plan meals with the patient, that they like and enjoy.
- snack boxes are available in the outpatients department and can be ordered by asking a member of staff.

Mouth care - please let staff know how the person likes to have their mouth cared for, as sometimes mouths can become dry and sore if a person is not eating and drinking well.

Changes in behaviour during a hospital stay

The hospital environment can be challenging as it is very unfamiliar to a person living with dementia. This can sometimes lead to changes in their behaviour, for example, they may start walking around the ward, we call this 'wandering'. They can start to shout and call out and may use language they would not use normally, and occasionally become agitated. We understand this can be very distressing for families and carers.

To support them if their behaviour does change, we may use individual nurses to provide the additional care that is needed at this time. We call this 'one to one care'. The nurse will stay with them and assist with personal care, walk with them if they wander and use activity to help distract and settle them.

Additional ways you can help:

- Clean spectacles and check hearing aids.
- Make sure clothes are discreetly labelled in case they are mislaid.
- Think of enjoyable pastimes or items to occupy the person's time.
- Provide them with their own day and night clothes to help them feel themselves.

Family, Carers and Friends Charter / Stay with Me

We welcome family and carers to stay and support their family member or friend.

The 'Family, Carers and Friends Charter' supports family or friends that are carers to stay with their cared for person outside visiting times, so you can be involved and included in their care. We understand that many families or friends do not consider themselves as carers. Please speak to a member of staff if we can support you with this.



UHL Carers Charter

'Stay with Me' builds on the charter, to help create a welcoming environment on all hospital wards, where there are no barriers for families who wish to stay beyond visiting times for patients with dementia.

The visiting times for a ward and number of visitors allowed will be displayed at the entrance, together with contact details for the ward.

Any family member staying beyond visiting times will be encouraged to rest. We would suggest leaving the hospital around 10pm and returning in the morning. Staying overnight will be discussed with you if the person with dementia is considered to need this support.



The whole team are here to treat and provide care. Please let us know how much you would like to be involved during their stay.

The Forget ME Not scheme

The 'Forget ME Not' scheme ensures the person living with dementia is given extra time and support. A Forget ME Not flower is a visual symbol to help all staff recognise a person with dementia. The flower symbol is placed at the bedside to remind all staff to take extra time when caring for the person with dementia.

All patients with a diagnosis of dementia are opted into the scheme, unless they or their family/ carer request not to take part. If you or your loved one does not wish to take part in this scheme please notify a member of staff. The choice is entirely yours.

If you choose not to have a Forget ME Not flower, please be assured that this will not affect the level of care that you or your loved one receives.



Meaningful Activities Service

The Meaningful Activities Service supports patients with a diagnosed dementia and those with a possible dementia and delirium.

The service aims to make everyday meaningful through activities that promote stimulation, whilst supporting a person's general wellbeing.



Activity is proven to give a person with dementia a sense of self worth and achievement and helps people to live well with dementia.

The team are mainly based in the Emergency Department and older peoples wards at Leicester Royal Infirmary. The other 2 sites, Glenfield Hospital and Leicester General Hospital, can access the Meaningful Activities Service through the outreach service.

We use the 'Know Me Better' Patient Summary to select activities that are 'meaningful' to each individual. For example, activities could be related to a person's previous job role, or their interests.

The Meaningful Activities Team, together with families, carers and ward staff, will find out more about a patient and write this into a 'Know Me Better' Patient Summary. This is kept with the patient's records and is accessible to staff, so please complete these with as much information as possible.

We welcome all feedback about this service. If you wish to leave feedback please ask your Meaningful Activities Facilitator for a feedback card.

Older People and Dementia Champions

Leicester's Hospitals has an Older People and Dementia Champions Network where staff voluntarily attend training.

Champions help to promote a dementia friendly hospital within their wards and departments, whilst positively influencing others of the needs of people with dementia and their families.

Older People and Dementia Champions are identified by staff wearing a badge.



Admiral Nursing Service

The Admiral Nursing Service is set up within our hospitals in partnership with Dementia UK. Admiral Nurses are there to support people with dementia and their families when things get difficult or challenging. They offer one-to-one support, advice and guidance that can be hard to find elsewhere.

Admiral Nurses support families to live more positively with dementia in the present, support them with decision making, and planning for the future. They work alongside the medical and nursing team. They can provide family and carers with useful information, or signpost you to services they work closely with.

For enquiries about the service, please speak to a member of staff on the ward, who can contact the Admiral Nurses by email.



Medication

Please bring the persons usual medication with you. This can help doctors when admitting someone to hospital to ensure their regular medication continues. Any changes to medication will be discussed with either the patient, family member or carer, as appropriate.

Discharge from hospital

A discharge date will be planned as soon as possible. However, decisions can often be made quickly, so please begin preparations as soon as the person goes into hospital.

To help prepare for discharge, you may see different hospital staff including a physiotherapist, an occupational therapist or a social worker. This team along with nursing and medical staff will help you have a safe and supported discharge from hospital.

If you would like to find out more information about dementia support services for when you leave hospital, please ask a member of staff to refer you to Age UK Dementia Support Team. They provide advice and support for people living with dementia and their carers while in hospital and upon discharge.

Further information and support

There are organisations who can help support people living with dementia and their carers. Contact details for some of these organisations are given below:

- **Dementia UK:** Offers information about living with dementia, and advice and support with any aspect of dementia. Specialist dementia nurses on their free, confidential helpline are here for you when you need help. Whatever you're worried about, they have the time to listen and the knowledge to solve problems. They can help you understand more about dementia and feel more in control, giving you the tools and confidence to manage your future with dementia together.

Dementia UK'S Admiral Nurse National Helpline: 0800 888 6678

Email: helpline@dementiauk.org

www.dementiauk.org

- **Alzheimer's Society:** Offers a wide range of services and information about living with dementia. They also provide opportunities if you would like to become more involved in local community initiatives.

Alzheimer's Society provides a Hospital Dementia Support Service to provide additional support for people living with dementia and their carers.

Alzheimer's Society National Helpline: 0300 222 11 22

www.alzheimers.org.uk

- **Carers support:** For further details and how to access a Carer's Assessment, please contact your local Social Services and ask for 'Single Point of Contact duty desk'. They will help guide you on how to obtain and complete this.

Contact numbers: 0116 454 1004 (City)
0116 305 0004 (County)
01572 722 577 (Rutland)

- **Age UK:** Leicestershire and Rutland offers a free, confidential and independent information and advice service which can assist with the following issues:

- welfare benefits (such as attendance allowance) and money matters.
- leisure and social activities.
- social care, residential and nursing care.
- local services.

Tel: 0116 223 7363 (weekdays - 8.30am to 5.30pm)

Email: dementiasupport@ageukleic.org.uk

- **CLASP:** The Carers Centre provides support for carers.

Tel: 0116 251 0999 / www.claspthecarerscentre.org.uk

- **Leicestershire Police:** Leicestershire Police have developed a tool to help them locate and support a person living with dementia, should they go missing from home. This is called the Herbert Protocol. This is a form that carers, family or friends of a vulnerable person, or the person themselves can fill in. It can be shared with police if ever needed. The form will help provide police with essential current and historical information about the missing person.

The form is available to download and complete from the link below, so it can be kept in the persons home. Keeping a completed form saves the worry of trying to recall information during the stressful time of someone going missing. Update the form regularly to make sure the information is always accurate.

<https://www.leics.police.uk/notices/af/herbert-protocol/>

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغة أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل
જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।
Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

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