Dementia

Information for people with dementia and their carers
Introduction

Leicester’s Hospitals, with support from Alzheimer’s Society Leicester and Age UK Leicestershire and Rutland has produced this information leaflet 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.

Symptoms of dementia may include the following:

- Loss of memory – this particularly affects 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.
What is dementia? (continued)

- Mood changes – people with dementia may be withdrawn, sad, frightened or angry about what is happening to them.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 describing the function of an item instead of naming it.

What causes dementia?

There are several diseases and conditions that result in dementia. 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.

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, following 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.
What causes dementia? (continued)

**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.

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**Can dementia be cured?**

Unfortunately there is no current cure, although improvements in management of symptoms continue. Research also continues into developing drugs, vaccines and other treatments. Drugs have been developed to temporarily alleviate some of the symptoms of some types of dementia, mainly Alzheimer’s disease and to reduce stroke risk in vascular dementia.
How can I tell if I have dementia

Many people fear they have dementia, particularly if they think that 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; memory loss can just be part of ageing, and it can also be a sign of stress or depression.

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<thead>
<tr>
<th>Signs of Alzheimer's</th>
<th>Typical age-related changes</th>
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<tbody>
<tr>
<td>Poor judgment and decision making</td>
<td>Making a bad decision once in a while</td>
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<tr>
<td>Inability to manage a budget</td>
<td>Missing a monthly payment</td>
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<tr>
<td>Losing track of the date or the season</td>
<td>Forgetting which day it is and remembering later</td>
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<tr>
<td>Difficulty having a conversation</td>
<td>Sometimes forgetting which word to use</td>
</tr>
<tr>
<td>Misplacing things and being unable to retrace steps to find them</td>
<td>Losing things from time to time</td>
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Dementia screening

If you are aged 75 and over and are admitted to our hospitals in an emergency a doctor will screen you to check for the early signs of dementia. This does not mean that you or your relative has dementia but it is important any early signs and symptoms are recognised.

A timely diagnosis can greatly improve the quality of life for the person with dementia and can offer support to carers and families.

Early diagnosis enables a person with dementia and their family to receive help in understanding and adjusting to the diagnosis and to prepare for the future in an appropriate way. This might include making legal and financial arrangements, changes to living arrangements and finding out about aids and services that will enhance quality of life for people with dementia and their family, carers and friends.

Early diagnosis can also allow the individual to have an active role in decision making and planning for the future while families can educate themselves about the disease and learn effective ways of interacting with the person with dementia.

Admission to hospital gives an opportunity to assess a person and ensure they have the appropriate care when they are discharged.
What does dementia screening involve?

Step 1
When you are admitted to hospital the doctor will ask you or your family, carer or friend the following question:

“Has the person been more forgetful in the last 12 months, to the extent that it has significantly affected their daily life?”

Step 2
If the answer to this question is yes then the doctor will carry out an assessment which includes:

• Cognitive tests – the doctor will ask a series of questions designed to test thinking and memory

• Physical examination and tests – the doctor will normally carry out a physical examination and may perform a number of tests, such as blood and urine tests, to identify other conditions that may be causing the symptoms

• Analysis of background information – the doctor may talk to you or your family, carer or friend, to try to establish some of the symptoms.

Step 3
If the assessment shows a possibility of dementia, you will be asked to see your GP to discuss this further. The hospital doctor will inform your GP in your discharge letter. The GP may then refer you on to a memory clinic or a community liaison team for a formal diagnosis and support.

If you have any questions about Dementia Screening, please speak to a member of staff.
Diagnosing dementia

It is very important to get a proper diagnosis of dementia. A diagnosis will help the doctor rule out any illnesses that might have similar symptoms to dementia, including depression. Having a diagnosis may also mean it is possible to be prescribed drugs 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, either a GP or a specialist. The specialist may be a geriatrician (a doctor who specialises in the care of older people), a neurologist (someone who concentrates on diseases of the nervous system) or a psychiatrist (a mental health specialist). 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 someone presents with a history or sudden decline in their memory we carry out blood tests to rule out any reversible reasons for memory decline.

We also talk to carers to gather information and build up a picture of the type and duration of decline in memory. We may arrange for a brain scan and specialist assessment by a psychiatrist. We may also send a request to your GP for referral to a memory clinic for on-going assessment and support.
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 but the evidence does indicate that a healthy diet and lifestyle may help protect against dementia. In particular, exercising regularly, avoiding fatty foods, not smoking, drinking alcohol in moderation and keeping mentally and socially active into old age may help to reduce the risk of developing vascular dementia and Alzheimer's Disease.

The above information has been provided by Alzheimer's Society. Please see www.alzheimers.org.uk for further information.

Being admitted to hospital

Hospital environments can be disorientating for a person with dementia, and they may appear to be more confused than usual, for example, on a busy ward or outpatient department. However, there is much that can be done to help a person with dementia adapt to the new environment.

Ward 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’.
Information about the person with dementia

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 behavior may indicate certain issues (such as being in pain, needing a drink or tiredness).

Know Me Better - Patient Summary

In emergencies, 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 on the ward, please ask a member of staff for a ‘Know me Better’ Patient Summary so you can tell us more about:

- How they like to be addressed… for example William may like to be called Bill
- How they communicate… what language do they speak? Do they wear glasses or use hearing aids? And how we would recognise if they were in pain.
- ‘Their usual routine and self care… what can they do for themselves and what might they may need help with.
- Relaxation and sleep… how do they like to relax? What makes them comfortable?
- Important things in their life… people, hobbies or interests.
- Emotional support… things that may upset them and things that make them calmer.
- Spiritual and cultural needs… how can we help support this
**Being admitted to hospital (continued)**

- Do they enjoy listening to music? What kind of music?
- Personal needs… will they need help to go to the toilet?
- Eating and drinking… tell us about their likes and dislikes, special dietary requirements or allergies
- Taking medication… how do they prefer to take medication

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<tr>
<th>Know me better Patient Summary</th>
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<tr>
<td>Patient details: This document is to be completed by / for people who cannot consistently communicate their own needs. Please be as thorough and descriptive as you like - the more information you provide, the more we can adapt the care we provide to suit you. If you need more space please ask staff for a 'Know Me Better Patient Profile'.</td>
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<tr>
<td>Name: ......................................................... I like to be called: ........................................ Date: ____________________________</td>
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<tr>
<td>S. Number: ____________________________ Completed by: ____________________________ The language I speak is: ____________________________</td>
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**Communication**

- Do you have any difficulty communicating? [ ] Yes [ ] No
- Do you have impairment of: [ ] Vision [ ] Hearing [ ] Other
- Do you use: [ ] Glasses [ ] Hearing aid(s) [ ] Details
- Do you mind wearing your glasses / hearing aid? [ ] Yes [ ] No

**Getting About**

- How do you normally get about:
  - [ ] Walk independently
  - [ ] Walk with a stick
  - [ ] Walk with a trolley
  - [ ] Stay in the chair or bed
  - [ ] Other

**My usual routine and care**

- I can: Wash myself [ ] Yes [ ] No
- Dress myself [ ] Yes [ ] No
- Toilet myself [ ] Yes [ ] No
- Clean myself after toileting [ ] Yes [ ] No
- Feed myself [ ] Yes [ ] No
- Cook for myself [ ] Yes [ ] No
- Shop for myself [ ] Yes [ ] No
- Clean for myself [ ] Yes [ ] No

**I live:**
- Alone [ ] Yes [ ] No
- With my spouse [ ] Yes [ ] No
- With family [ ] Yes [ ] No
- In a residential home [ ] Yes [ ] No
- In a nursing home [ ] Yes [ ] No

**I require help at home from:**
- ........................................................................

**My bladder and bowels:**
- I require help to the toilet [ ] Yes [ ] No
- I use pads to keep me dry [ ] Yes [ ] No
- I have a catheter [ ] Yes [ ] No
- I sometimes leak urine/faeces [ ] Yes [ ] No
- I often need to rush to the toilet [ ] Yes [ ] No

**I have carers:**
- Yes [ ] No [ ]

**How many carers visit?**
- .................................................................
- ................................................................. per day

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**Providing reassurance**

Familiar objects, 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. They can also provide staff with a good talking point. If the person still reads, provide a notebook, so staff and visitors can write messages, reminders and details of when they are next visiting.

**Please avoid bringing valuable items or irreplaceable photographs as occasionally items can become misplaced.**
In hospital, nurses use assessments and care plans to help deliver safe and effective care to patients. This helps to deliver individualised care.

Being admitted to hospital where the environment and people are unfamiliar can be very upsetting for 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 patients can become aggressive. We understand this can be very distressing for families and carers.

To support the person with dementia if their behaviour does change we 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 to and assist with personal care, walk with them if they wander and use activity to help distract and settle them.

**Eating and drinking**

We acknowledge that some people with dementia may require extra support at mealtimes. We provide red trays, cups and jug lids on each ward to help identify those patients who need extra support. We also have ‘enhanced mealtimes’ where patients can enjoy their meals with minimal interruption.

In addition, on many wards, we have mealtime volunteers who have been specifically trained to help people who need assistance with their food and drink to improve patients’ mealtime experience.
Eating and drinking (continued)

Please make the ward staff aware of any difficulties that the person you care for has at mealtimes and how they can help. **Tell them the likes and dislikes of food or drinks, whether reminders or prompts to eat are required or if there are any swallowing difficulties.**

You can get involved by helping your loved one to choose meals and snacks they enjoy and writing them down so we can make sure they are ordered.

Please ask a member of staff for a seven day meal planner.

Sometimes a sign may be placed above the bed saying ‘Nil by Mouth’ (or NBM) or restricted fluids for example. These signs are usually placed for a medical reason or if the person is to undergo investigations or operations.

If you notice the person you care for is not eating well, please tell us so we can refer them to our Dietitians to help coordinate a nutritional plan.

Practical assistance

It is possible for carers to help with care should they wish to (for example, helping getting dressed or support at mealtimes). If you would like to do this, please discuss with the Nurse in Charge.

**Other ways in which you can help might include:**

- Clean spectacles and check on hearing aids
- Make sure clothes are discreetly labeled in case they are mislaid
- Think of enjoyable pastimes or items to occupy the person’s time
The Carers Charter and Stay With Me

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

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

‘Stay with Me’ builds on the Carers 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.

Ward visiting times/numbers of visitors allowed are displayed at the entrance alongside contact details for the ward.

The family member staying beyond visiting times will be encouraged to rest and we would suggest leaving the hospital around 10pm and returning in the morning. Staying overnight will be discussed with you if your loved one is considered to need this support.

The whole team are here to treat and care for your loved one, please let us know how much you would like to be involved during their stay.
The Carers Charter and Stay With Me (continued)

Please follow this important information to ensure that your safety and that of all patients on the ward is maintained.

Safety

- As you will be on the ward at times outside of the normal visiting hours please let the nursing team know each time you arrive and leave to ensure that in the event of a fire/emergency we know if you are on the ward
- This is a non-smoking hospital; should you need to smoke, including the use of e-cigarettes or vapes, please use the smoking shelters provided or leave the hospital grounds. A member of staff will be able to tell you where the nearest shelter is
- Please do not attempt to lift or reposition your loved one on your own during their stay; ask a member of staff to safely reposition them. The Occupational Therapist and Physiotherapist will be happy to advise you on how you can help

Privacy and Dignity

- To respect the privacy and dignity of all patients on the ward there may be times when we will ask you to leave the bedside. For example if another patient requires a consultation or treatment. It is important that you comply with these requests
- Please keep your phone on silent during your stay. If you have to make a telephone call please leave the bedside to minimise disruption to other patients
- All patients in hospital need time to rest and recuperate; please be mindful of noise levels whilst you are on the ward to prevent disruption to other patients.
The Carers Charter and Stay With Me (continued)

Preventing Infection

Infection prevention is very important in the hospital setting. Staff will advise on the use of Personal Protective Equipment (gloves and aprons) and hand hygiene. If your relative is in a side room and/or source isolated please ask the ward to contact infection prevention and someone from the team will advise you of the precautions needed.

Always use alcohol sanitiser before contact with your loved one and when leaving the bed space. Please wash your hands before supporting your loved one with food and drink and after helping with any personal care and using toilet facilities.

If you are unwell, please do not come to the ward. Please telephone the ward who will advise about visiting the ward.

Occasionally wards need to implement restricted visiting due to infection. A member of staff will discuss how this will affect you and any changes that may need to be made to extended visiting during this time.

Car Parking

The Trust offers a variety of concessionary parking tickets for prime carers (only one will be issued per patient however this can be shared between carers i.e. person x uses during day and passes to person y for the night), should the patient remain in hospital for six or more weeks there is a free parking permit available.

We aim to make the ward a comfortable and welcoming place for our patients’ family members and carers.

If you have any concerns during your stay discuss them with a member of staff who will be happy to help.
People living with dementia and their families know how important it is that others know they have dementia in order to provide the right care and support.

In our hospitals to support people living with dementia to be recognised we have a ‘Forget ME Not’ scheme to ensure the person with dementia is given extra time and support.

We use a forget me not flower as a visual symbol to help all staff in the hospital recognise a person with dementia.

The flower symbol is placed at the bedside to remind all staff to take extra time when communicating with patients who may have difficulty expressing their needs or understanding and retaining information. Staff will offer additional support with eating and drinking, personal care and going to the toilet. When patients need to be accompanied off the ward for investigations non ward staff are also aware.

**What does the ‘Forget ME not’ scheme involve?**

All patients with a diagnosis of dementia are opted into the scheme, unless they or their family/carer request not to take part. Please let a member of the ward staff know if you do not want to be involved.

- A discreet forget me not flower is placed on the front of the medical notes
- A forget me not flower is placed behind the bed
- A blue patient identity band is worn instead of the usual white wrist band, this helps when patients leave the bedside e.g to go for an x-ray.
Forget ME not scheme (continued)

What if you choose not to be involved in the scheme?

Please be assured that choosing not to have a Forget Me Not will not affect the level of care that you or your loved one receives. 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.

Having a forget me not acts as a reminder to staff that you or your loved one has a diagnosis of dementia and will remind staff of our FORGET approach.

Family, friends and carers involvement
Good open communication with patients, carers, family and staff.

Orientate
Orientate to day, time and place. Encourage patients to get dressed and sit out of bed. Ensure patients call bell is within reach and toileting is offered.

Reassure
Reassure patients with a smile you’re there to help.

Get to know me better
Encourage family to bring in familiar things in from home. Complete Know Me Better Patient Summary.

Explain
Introduce yourself and ask what the patient likes to be called. Gain consent. Explain what you are doing and why.

Time
Take time to offer a drink or snacks. Ensure patients are offered assistance at meal times. Promote good nutrition and hydration, offer 7 day meal planner.

...ME Not
About the team

The Meaningful Activities Service supports patients with a diagnosed dementia and those with a possible dementia, delirium, or increased confusion.

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

Our Meaningful Activities Facilitators are mainly based on the older peoples wards at Leicester Royal Infirmary. Wards that do not have an allocated facilitator can access the Outreach Service at Leicester Royal Infirmary and Glenfield Hospital.

If your ward has a Meaningful Activities Facilitator, a poster with their name and photograph will be displayed by the dayroom so you can identify them.

When are we available

The Meaningful Activities Service is available at: Leicester Royal Infirmary, Monday - Friday between 09.00-16.00 and Glenfield Hospital on various weekdays from 09.30-16.00.

Please speak with your Nurse in Charge if you have any queries about this.

Patient Summary

The Meaningful Activities Service, with families, carers and ward staff, will find out more about patients and write this into a ‘Know Me Better’ Patient Summary. This is kept in a patient’s nursing folder and is accessible to staff, so please complete these with as much information as possible.
Activities

Activity is proven to give a person with dementia a sense of self-worth and achievement and helps people to live well with dementia. Please look out for the Meaningful Activity Facilitator on your ward.

We use the 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 service carries out a variety of activities with patients such as:

- Arts and crafts (e.g. card making, painting)
- Games and puzzles (e.g. playing cards, jigsaws)
- Reminiscence (e.g. reading, discussions)
- Sensory (e.g. hand massage, Twiddle muffs, sensory dolls)
- Providing reassurance during mealtimes or personal care.

Activities can be carried out individually or in groups, either at the bedside or in the dayroom.

Patients who are isolated due to an infection may be restricted in the activities they can take part in due to the risk of spreading the infection to others.

Once an activity has finished, the Meaningful Activities Facilitator will feed back to the nurse looking after the patient.

Forget Me Not Volunteers

The Meaningful Activities Service is supported by Forget Me Not volunteers, who work directly with us to carry out activities on the wards.
Observers

On occasion there may be an observer with a Meaningful Activity Facilitator, who is learning about the service in more depth. It is expected that they will get involved in activities with patients. If you have any queries about this then please ask your facilitator.

Feedback about the service

We welcome all feedback about the Meaningful Activities Service. If you wish to leave feedback then please ask your Meaningful Activities Facilitator for a feedback form or card. For anybody wanting to provide anonymous feedback then please post these to:

Meaningful Activities Service
Patient Experience Office
Knighton Street Outpatients
Leicester Royal Infirmary
Infirmary Square
Leicester
LE1 5WW

Dementia Champions

Leicester’s Hospitals has a Dementia Champion Network where staff voluntarily attend training to become a champion for people with dementia and their carers.

They 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.

Dementia champions are identified by staff wearing a badge or a lanyard.
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 for you or your relative 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 the Alzheimer’s Society Hospital Dementia Support Team as 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 people who can help support people living with dementia and their carers. Here are some of the organisations available to help:

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. For more information call the team on 0116 231 6925 / 0116 258 7519

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: 0116 454 1004 (City)
0116 305 0013 (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), money matters, leisure and social activities, social care, residential and nursing care and local services.
Visit the Age UK resource Centre, level 0, Windsor Building, Leicester Royal Infirmary
Please telephone 0800 169 2081
Website www.ageuk.org.uk

CLASP
The Carers Centre provides support for carers.
Call: 0116 251 0999 or visit: www.claspthecarerscentre.org.uk

Leicestershire Police
Leicestershire Police have developed a tool to assist them to locate and support a person living with dementia should they go missing from home. This is called the Herbert Protocol
The Herbert Protocol provides essential current and historical information about the person living with dementia that family, friends, carers can share with the police if needed. E.g Previous addresses, places of work, places of significant
The Herbert Protocol is available to download to be completed and kept in the persons home so that it is available should it be needed
https://leics.police.uk/advice-and-information/victims-witnesses/advice-carers-people-dementia
If you have any questions, write them down here to remind you what to ask when you speak to your nurse/consultant.
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Today’s research is tomorrow’s care

We all benefit from research. Leicester’s Hospitals is a research active Trust so you may find that research is happening when you visit the hospital or your clinic.

If you are interested in finding out how you can become involved in a clinical trial or to find out more about taking part in research, please speak to your clinician or GP, or call 0116 258 8351.

If you would like this information in another language or format, please contact the service equality manager on 0116 250 2959.

إذا كنت ترغب في الحصول على هذه المعلومات في شكل أولعية أخرى، برجى الاتصال مع مدير الخدمة للمساواة في 0116 250 2959.

If you have any queries, please speak to your clinician or GP, or call 0116 258 8351.

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