

Dementia information leaflet

Patient and carer information

Dementia
education
team



Contact Details

Ward/area name: _____

Telephone number: _____

Introduction

South Tees Hospitals NHS Foundation Trust has produced this information leaflet for people affected by dementia. We hope this will help you understand more about dementia, as well as providing information to make a stay in hospital for the person with dementia as comfortable as possible.

What is dementia?

Dementia is a common condition. It is caused by a number of diseases, including Alzheimer's disease, or when damage is caused by a series of small strokes. The risk of developing dementia increases as the person gets older.

The term dementia is given to a group of related symptoms associated with an ongoing decline of the brain and its abilities. This includes problems with:

- memory loss;
- thinking speed;
- mental agility;
- language;
- understanding;
- judgement.

Dementia is progressive, which means the symptoms will gradually get worse. There is no cure at present for dementia, but with support those affected by dementia can live well.

What causes dementia?

Dementia is caused by gradual changes and damage in the brain. The most common causes of dementia include diseases in which the brain cells degenerate and die more quickly than they would as part of the normal ageing process. The changes usually happen because of a build-up of abnormal proteins in the brain. This damage leads to a decline in a person's mental and, sometimes, physical abilities.

Causes of Alzheimer's disease

Alzheimer's disease is the most common type of dementia. It affects the brain cells responsible for storing memories, as well as the nerves and transmitters which carry instructions around the brain.

These nerves and transmitters are responsible for processing thoughts and many of the complex functions of our brains, such as storing and retrieving memories, calculation, spelling, planning and organising.

Causes of vascular dementia

Vascular dementia is caused when the brain's blood supply is interrupted. Like all organs, the brain needs a constant supply of oxygen and nutrients from the blood to work properly. This can happen when a stroke interrupts the flow of blood to the brain, or when tiny blood vessels which lie deep in the brain become damaged.

Causes of dementia with Lewy bodies

Lewy bodies are small, circular lumps of protein that develop inside brain cells. It is not known what causes them. It is also unclear how they damage the brain and cause dementia.

Dementia with Lewy bodies is closely related to Parkinson's disease. This is a condition, where part of the brain becomes more and more damaged over a number of years, leading to physical symptoms, such as involuntary shaking (tremor), muscle stiffness and slow movement. A person with dementia with Lewy bodies may also develop these symptoms.

Causes of frontotemporal dementia

Frontotemporal dementia is caused by damage and shrinking in two areas of the brain. The areas of the brain affected are called the temporal lobe and the frontal lobe.

Frontotemporal dementia is one of the more common types seen in people who are under 65 years of age. In an estimated 20% of cases, people who develop frontotemporal dementia have inherited a genetic mutation from their parents.

Diagnosing dementia

If you are worried about your memory or think you may have dementia, it's a good idea to see your GP. If you're worried about someone else, who you think has dementia, encourage them to make an appointment and perhaps suggest that you go along with them.

If a person is forgetful, it doesn't mean they have dementia. Memory problems can also be caused by depression, stress, drug side effects, or other health problems. It can be just as important to rule out these other problems or find ways to treat them. The GP will be able to run through some simple checks and either reassure, give a diagnosis, or refer on to a specialist.

Dementia can be difficult to diagnose, especially if symptoms are mild. If the GP is unsure about the diagnosis, they will refer on to a specialist such as a neurologist (an expert in treating conditions that affect the brain and nervous system), an elderly care physician, or a psychiatrist with experience of dementia.

Once the necessary tests are completed, the doctor should ask if the person with memory problems wants to know the diagnosis. They should explain what having dementia might mean, and should give the person with memory problems time to talk more about the condition and ask any questions they may have.

Written information should also be given out at diagnosis. Further information is available from the Alzheimer's Society (2013, *The Dementia Guide*).

Lasting power of attorney

A Lasting Power of Attorney (LPA) is a legal tool that allows you to state who you would like to make decisions on your behalf, should you become unable to do so in the future. There are two different types of LPA: property and affairs LPA and health and welfare LPA. Each type covers different decisions and there are separate application forms for each. You can choose to make both types, or just one.

There are a number of reasons you may wish to make an LPA:

- it can be reassuring to know that, if you are unable to make a decision for yourself in the future, your chosen person will make these decisions for you;
- making an LPA ensures that the person you want to make decisions for you will be able to do so;
- an LPA can reduce problems that may occur in the future. It can be more expensive and time-consuming for family or friends to try to gain a similar power in the future;
- making an LPA can help prompt discussions with your family or others about your future wishes.

An early diagnosis gives the person with dementia the best chance to prepare and plan for the future, and receive any treatment. With treatment and support from healthcare professionals, family and friends, many people are able to lead active, fulfilling lives.

Being admitted to hospital.

We know that a stay in hospital can be upsetting.

South Tees Hospitals NHS Foundation Trust can provide a **Forget-Me-Not card** to help us get to know the patient better.

Directorate of quality assurance
Nursing and patient safety

South Tees Hospitals NHS Foundation Trust

'Forget me not'

Hello. My name is

This leaflet will help to support you during your hospital stay

Things I'd like you to know about me:

- I prefer to be called
- I now live in
- I was born and grew up in
- I work / worked as a

together we do the amazing

This can also reduce the disorientation a person with dementia may feel when being admitted to hospital.

Ask a member of the ward staff for a card to complete.

Ward staff are happy to answer any questions and discuss any issues you may have. If at times you feel they are too busy to talk, please do ask to make an appointment.

If you notice increased confusion in the person you care for, please tell the nurse or doctor. This may be related to a progression in dementia, but it could also mean an underlying medical problem that we may be able to treat. The medical problem is often described as 'delirium'.

For more information on preparing for a visit or stay in hospital, please refer to the "South Tees Hospitals NHS Foundation Trust. Preparing for a visit or stay in hospital. Information for patient with memory problems and their carers" leaflet.

Practical assistance

It is, in most situations, possible for a carer to help with care (for example, helping with dressing or support at mealtimes). If you would like to do this, discuss it with the nurse in charge.

Familiar objects, such as copies of old photographs of family members or a much-loved pet placed on a 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.

Other ways in which you can help include:

- making sure the person's own clothes (including day clothes and shoes) are available from home;
- cleaning glasses and checking hearing aids;
- making sure clothes are discreetly labelled in case they are mislaid;
- thinking of enjoyable pastimes or items to occupy the person's time.

Eating and drinking

We acknowledge that some people with dementia may require extra support at mealtimes. We provide a red tray system on each ward which identifies those patients who need extra support. We also have protected mealtimes where patients can enjoy their meals with

minimal interruption. If you would like to help at mealtimes you can discuss this with the nurse in charge.

Please make sure ward staff are aware of any difficulties that the person you care for has at mealtimes and how this may be overcome. Tell them the person's likes and dislikes, whether reminders or prompts to eat are required, or if there are any swallowing difficulties. Inform ward staff if the person with dementia is under the care of the dieticians and requires any supplementation or special diet. If you notice the person you care for is not eating well, please let the nurse looking after them know.

For more information on overcoming problems with eating and drinking in dementia, please refer to the "South Tees Hospitals NHS Foundation Trust. Eating and drinking in dementia. Patient information" leaflet.

Medication

Please bring the person's usual medication with you (or at least a list of their current medication and dosages). This can help to ensure regular medication continues. Any changes to medication should be discussed with either the patient or carers, as appropriate.

Discharge

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, and a social worker. This team, along with the nursing and medical staff, will help you have a safe and supported discharge.

Driving and dementia

A diagnosis of dementia is not in itself necessarily a reason to stop driving. What matters, from both legal and practical points of view, is whether or not the individual is still able to drive safely. However, they must fulfil certain legal requirements, including telling the Driver and Vehicle Licensing Agency (DVLA) in England, Scotland and Wales, or Driver and Vehicle Licensing Northern Ireland (DVLNI) in Northern Ireland, of their diagnosis. If they refuse they could be fined up to £1,000.

A person with a diagnosis of dementia should also immediately inform their car insurance company. If they do not, their policy may become invalid. It is a criminal offence to drive without at least third party cover.

Caring for carers

At South Tees Hospitals NHS Foundation Trust, we recognise and value the role carers have in the health, comfort and wellbeing of our patients.

Please see <http://southtees.nhs.uk/patients-visitors/carers-supporting-your-needs-and-rights> for more information.

The trust defines a carer as a person of any age who provides help and support to a parent, child, partner, relative or close friend because of their illness, frailty or disability, who is not employed to provide this care.

If you are or think you may be a carer, please make yourself known to staff and ask for a carers' information card.

Open access/visiting

Where possible, our staff will facilitate open access and unrestricted visiting to enable carers to maintain and contribute to the care of their relative or friend when they are in hospital.

We also try to allow carers to accompany their loved ones at tests or investigations, staying overnight with relatives where possible.

Further information

We understand carers sometimes need a break. We appreciate your help, but please tell us if you need to rest. We offer a carers' information card with a map including key information such as restaurants, cafes and parking pay points within the hospital.

We can also signpost you to support services in Middlesbrough, Redcar & Cleveland and Hambleton and Richmondshire.

By law, carers are entitled to a carers' assessment by their local authority. This should help carers understand what financial and emotional support is available and also offer details around community-based support groups offering extra help and support. This includes charities and organisations outside of the hospital trust who may be able to assist you and your family.

If your loved one is going to require long periods in hospital or numerous outpatient appointments, we can also offer reduced rates on car parking at James Cook and The Friarage Hospital.

Trinity Holistic Centre, on the James Cook site also welcomes carers to its quiet space, providing complimentary therapies – or just a chat and a cup of tea or coffee. Additionally, the chapels on both the Friarage and James Cook sites offer quiet spaces.

Carers' Associations

If you are caring for someone with memory problems, and you would like additional support and information, the following organisations cover this area:

Alzheimer's Society – Local offices

Middlesbrough:

Email: darlingtonteesside@alzheimers.org.uk

Telephone: 0191 389 0400

Hambleton & Richmondshire:

Email: richmond@alzheimers.org.uk

Telephone: 01748 825 817

Carers Together, Redcar

Email: carerstogether@btconnect.com

Telephone: 01642 488977

For people living with memory loss, and for their families and carers, finding out about the help available can be difficult. Carers Together provide information and support, face-to-face and by phone or email, to people who have concerns about their memory, have a diagnosis of dementia or are caring for someone with memory problems.

Sanctuary Supported Living, Middlesbrough

Email:

dementia.adviserservice@sanctuary-housing.co.uk

Telephone: 01642 223544

Sanctuary offer support with your welfare benefits; support to access a Carers Support Plan; access to employment and training; help to deal with letters and forms; referrals to other agencies to meet your needs; establish social contacts and activities; emotional support; housing related issues/adaptations; support with budgeting and debt issues; information regarding respite; access to training courses for carers; support to access Carers Emergency Cards; advocacy; and help with planning for the future.

Hambleton and Richmondshire Carers

Email: info@hrcarers.org.uk

Telephone: 01609 780872

When you are caring for someone it can be overwhelming and it can really help to have someone else to guide you to exactly what you need. Hambleton and Richmondshire Carers have direct contact with many national and local agencies that will be able to offer specialist support. Their specialist trained team can offer you a support service that is tailor made to suit you, wherever you are on your journey as a carer.

Age UK, Teesside

Email: front.office@ageukteesside.org.uk

Telephone: 01642 805500

Age UK Teesside is an organisation working with and for older people developing and delivering services and activities in consultation with or response to the needs of people aged 50+ living in Hartlepool, Stockton, Middlesbrough and Redcar and Cleveland. Their aim is to promote wellbeing and independence, ensuring later life is a fulfilling and enjoyable experience.

NHS Direct

Telephone: 111

Website: www.nhs.uk

Offers health information and advice from specially trained nurses over the phone 24 hours a day.

Dementia UK

Helpline: 0800 888 6678

Website: helpline@dementiauk.org

This leaflet has been replicated with the kind permission from University Hospitals of Leicester NHS Trust and with information from the Alzheimer's Society, UK.

Comments, compliments, concerns or complaints

South Tees Hospitals NHS Foundation Trust is concerned about the quality of care you receive and strives to maintain high standards of health care.

However we do appreciate that there may be an occasion where you, or your family, feel dissatisfied with the standard of service you receive. Please do not hesitate to tell us about your concerns as this helps us to learn from your experience and to improve services for future patients.

Patient Advice and Liaison Service (PALS)

This service aims to advise and support patient, families and carers and help sort out problems quickly on your behalf.

This service is available, and based, at The James Cook University Hospital but also covers the Friarage Hospital in Northallerton, our community hospitals and community health services. Please ask a member of staff for further information.

Patient Advice and Liaison Service (PALS)

If you have any questions, problems or concerns about your care or the care of the person you are looking after please contact the ward manager or PALS.

Email: stees.pals@nhs.net
Freephone: 0800 0282451
Telephone: 01642 854807 / 01642 282657
Post: Patient advice and liaison service (PALS)
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