

Understanding Advanced Dementia

Carer Information

Admiral Nurse Service



The Patient Information Leaflets page on the Trust website is available on the link:
<https://www.wwl.nhs.uk/patient-information-leaflets> or scan the QR code.

Author ID: MO
Leaflet Ref: Med 007
Version: 5
Leaflet title: Understanding Advanced Dementia
Date Produced: October 2025
Expiry Date: October 2027

Our Values

**People at
the Heart**

**Listen and
Involve**

**Kind and
Respectful**

**One
Team**

Understanding advanced dementia

Your loved one may have been diagnosed with dementia, either a while ago, or whilst they are currently in hospital. This leaflet is to give you information about how the disease may progress, how to understand potential issues that will need to be addressed, and how and where you can get support and advice.

How does dementia progress?

Dementia is a progressive illness which cannot be cured, although the symptoms can be managed a lot of the time. Each person with dementia is unique, and the way in which the disease progresses will be unique. It will also depend on the type of dementia, the age when the dementia developed and the general health and well being of the person prior to diagnosis.

What does advanced dementia mean?

This means that the damage to the brain is now significant and that the person is unable to manage independently and needs support in all aspects of their care.

What are the symptoms?

- The memory loss may become more significant and they may not be able to recognise loved ones or identify everyday objects. They may believe they are living in a past time period.
- They may lose the ability to speak and communicate.
- They may gradually lose the ability to move and walk.
- They may have difficulty swallowing and chewing food leading to repeated chest infections.
- They may become incontinent as they do not recognise a full bladder or bowel.
- They may spend a lot of time sleeping.
- Their behaviour may change significantly becoming restless, agitated, and have hallucinations.

How can we support someone with advanced dementia?

The Trust has an Admiral Nurse Service to support patients and their loved ones dealing with Advanced Dementia. Even if your loved one cannot communicate with you, continue to find ways in which you can still communicate with them. Touch is an important way of communicating with someone, as is just being there. If you find it difficult to talk to the person, then listen to music or read out loud to break the silence.

Deteriorating from advance to end stage dementia

When a person reaches the final or end stages of dementia, the main priority is the persons comfort, dignity and quality of end of life care. The decision that this stage has been reached will be made by the consultant and team caring for your loved one. In these final stages, complex care needs can be identified and the team will determine if certain medical interventions would be effective or not and whether they would cause further suffering.

Decisions that may need to be made

Cardiopulmonary resuscitation (CPR) will be discussed and the decision is usually made that there would be no benefits of this should the person suffer a cardiac arrest.

As the person enters this stage, they may not wish or be able to eat and drink normally. They may lose the ability to recognise hunger or thirst. We also know that:

- Hospital admissions in those with advanced dementia may not be appropriate and can be very distressing for the person.
- Tube feeding is not beneficial.
- Keeping someone well fed and making sure they have enough to drink may not be possible in advanced dementia.

As the brain starts to shut down, things such as eating and drinking may become impossible. The focus then needs to change to ensure that the person is comfortable. This means only giving essential medication, keeping the person pain free and comfortable.

Palliative care in end stage dementia

Palliative care is making the patient comfortable, ensuring that they have a 'good' death with the focus being treated with compassion, kindness and respect. There is a particular emphasis on actively, doing things to relieve (palliate) discomfort or distress whatever the cause. This means addressing symptoms as they arise. The team, whether they are community based or hospital based will also be there to support the family and carers through this time.

The Trust supports Johns Campaign which supports visiting outside of normal hours for relatives and carers of patients with a Dementia Diagnosis <https://johnscampaign.org.uk>

Further help and advice can be obtained from:

In hospital

Admiral Nurse (Clinical Nurse Specialist for Dementia) Bleep 2507

External - 01942 778612

Palliative Care Team - 01942 822008

Community Better at Home Single Point of Access – 0300 707 1221 (8am to 8pm)

If out of these hours (8pm to 8 am)

Out of hours GP 01942 829911

Social services 01942 828777

Dementia Uk: www.dementiauk.org

Dementia UK Helpline: 0800 888 6678

Mon-Fri 9am-9pm / Sat-Sun 9am-5pm

Alzheimers Society: www.alzheimers.org.uk

Alzheimers Society Helpline: 01942 247 837

Mon-Fri 9am-5pm / Sat-Sun 10am-4pm

Comments, Compliments or Complaints

The Patient Relations/Patient Advice and Liaison Service (PALS) Department provides confidential on the spot advice, information and support to patients, relatives, friends, and carers.

Contact Us

Tel: 01942 822376 (Monday to Friday 9am until 4pm)

The Patient Relations/PALS Manager
Wrightington, Wigan and Leigh Teaching Hospitals NHS Foundation Trust
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Ask 3 Questions

Become more involved in decisions about your healthcare. You may be asked to make choices about your treatment. To begin with, try to make sure you get the answers to three key questions:

1. What are my options?
2. What are the positives and negatives of each option for me?
3. How do I get support to help me make a decision that is right for me?



How We Use Your Information

For details on how we collect, use, and store the information we hold about you, please see patient information leaflet, Ref. **Corp 006** How we use your information, this can be found on the Patient Information Leaflets page on the Trust website, see details on the front cover.

This leaflet is also available in audio, large print, Braille, and other languages upon request. For more information, please ask in the department/ward.

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