Wrightington, Wigan and Leigh Teaching Hospitals
NHS Foundation Trust

Understanding Advanced Dementia

Version number: **5**
Last modified date: **12th November 2026**

Carer Information

Admiral Nurse Service

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

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 resucitation (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



Version number: **5**
Last modified date: **12th November 2026**

All rights reserved © 2026
WWL Teaching Hospitals NHS Foundation Trust