

Wrightington, Wigan and Leigh Teaching Hospitals NHS Foundation Trust

Accessible patient information sheet

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Dementia as a Palliative Condition – What you may need to know

Elderly Care Services

Introduction

Dementia is an umbrella term for any condition that causes memory loss, of which the most common form is Alzheimer Disease. There are many different types and different causes for the condition and although it can be managed for many years, it is a palliative condition (incurable) and eventually moves from affecting memory and thought processes to causing damage to the other functions the brain controls, such as kidney function and digestion.

The average life expectancy is between four and eleven years from the onset of the disease. This leaflet aims to help you understand what is happening to a person when they reach the final stages of the disease and how this might be managed. The aim is always to maintain a persons quality of life for as long as possible while maintaining their dignity and reducing the need for unnecessary treatments.

Dementia - the advancing condition and end of life issues

The following are the indicators that dementia may be getting worse:

- Unable to walk without assistance
- Incontinence
- Unable to talk or understand
- Needing full help with daily activities such as eating, washing & dressing

We would expect to see all of these things happening at the same time without any reversible cause - plus any one or more of the following:

- At least 10% weight loss in previous 6 months without other cause
- Recurrent infections such as urine infections, chest infections as food is continually going into the lungs due to their poor swallowing (aspiration pneumonia)
- Severe pressure ulcers
- Not wanting to eat & drink

We also know that:

- Swallowing problems (dysphagia) are very common in patients with dementia
- This can get worse as the dementia progresses
- Hospital admission due to poor swallowing in patients with advanced dementia may not be appropriate
- Tube feeding in patients with advanced dementia is not usually beneficial

Keeping someone well fed and making sure they have enough fluids in advanced dementia may not be possible

What about artificial feeding and fluids?

Tube feeding is unlikely to:

- Prevent chest infections (in fact it can make them worse)
- Improve a persons' general health
- Increase the survival time
- Prevent or improve pressure ulcers
- Reduce the risk of infection
- Improve their ability to do things for themselves
- Improve comfort of the patient

There is also good evidence that people with dementia do better in familiar surroundings than those who are sent to hospital, particularly those with chest infections.

So what is the answer?

We have to accept that sometimes we cannot continue to feed patients with advancing dementia. The areas of the body controlled by the brain start to shut down so even if we continue to put food and drink into them, their body will not utilise it. We can also cause them more discomfort by doing this such as vomiting, lungs full of fluid and swollen limbs.

We therefore change our focus from cure to comfort at this time and concentrate on what keeps the patient comfortable. This means not forcing them to take unnecessary medication. Also accepting when they don't want it and keeping their mouth clean and moist with good mouth care instead.

Carers' passport

The carers' passport can be used by carers to record the special needs, preferences and ways of communicating with the person they look after, if the patient themselves cannot communicate with staff.

Mealtimes

Although the Trust does not allow visiting at mealtimes, if your relative requires assistance with feeding, please speak with the ward staff who will allow you to remain on the ward at mealtimes to assist your relative/friend.

More information

For more information, please visit our website at:

<https://www.wvl.nhs.uk/Specialities/dementia.aspx>

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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 to 4pm)

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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 pros and cons 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 take a look at our "how we use your information" leaflet which can be found on the Trust website: https://www.wvl.nhs.uk/patient_information/leaflets/

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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Call 1 1 1 first, for health advice and reassurance when it's less urgent than, 9 9 9.

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