

Preparing for End Stage Dementia


Information for the family and carers' of people with Dementia.

A guide to planning ahead for relatives and carers on behalf of a person with end stage dementia



A Patient/Relative Information Leaflet produced for the people of Torbay and Southern Devon

South Devon Healthcare 
NHS Foundation Trust

Torbay and Southern Devon 
Health and Care
NHS Trust



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Introduction

The involvement of family, carers and friends is always important when providing good end of life care. Your knowledge of the person's life story and their expressed wishes and preferences can help professionals provide the best possible care. It is often difficult to talk about dying, but talking and planning can help you begin to understand end stage dementia.

Not everyone will want to engage in such a conversation and that's fine.

However, knowing what to expect can help to alleviate any anxieties of what you may see or experience. This can assist you in providing a positive and supportive role especially when someone close to you is approaching the end of their life.

The information in this leaflet is designed to support the Best Interests Decisions making booklet and is a general guide because everybody's dementia, including the end stage of their illness, is different.

For further information, you can either contact the organisations detailed on page 6, or you may prefer to discuss with your GP.

Care at the End of Life

End of Life Care aims to keep the person comfortable and pain free, but not to prolong life. This approach aims to give the person the best quality of life possible, but it recognises that the person will eventually die as a result of the disease they have.

End of Life Care:

- provides relief from pain and other distressing symptoms.
- aims to enhance quality of life and maintain dignity throughout.
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- acknowledges that dying is a natural process

Towards the end of the dementia illness treatment and care focuses on relieving symptoms. As a family, friend or carer, you are likely to know the person well. Your awareness and sensitivity to the often subtle changes in your relative's or friend's behaviour such as, facial expression and body language, makes you ideally placed to help us provide appropriate and good end of life care.

The dying process

No one can tell you exactly when death will occur. In the final stage of dementia, signs such as swallowing problems, weight loss and muscle weakness indicate the general health of the person is failing.

A person with end stage dementia may become uninterested in food and fluids at this time. It has been suggested that this is also a sign that the body is beginning to prepare for death. If the person with dementia has other major diseases like heart or lung disease; they may die because of these conditions before the final stages of dementia are reached.

Any infections the person experiences may occur throughout these final months of life, and will be treated according to the person's needs and their best interests.

Eventually no amount of treatment, even if the person is in a hospital will be able to prolong life.

At this time, the person will no longer want to eat or drink, and may seem to sleep all of the time. A person who is no longer eating or drinking may continue to live for some time, but can be comfortable.

What is end stage dementia?

Degenerative Dementias are progressive conditions that cannot be cured and people with dementia will have a shortened life span.

The changes that occur

While each person's experience of dementia is different, at this stage of the condition the person is likely to exhibit severe memory disturbances and the physical side of the condition may have become more obvious.

Some symptoms that a person with end stage dementia may experience include:

- Severe memory problems
- limited verbal skills
- little awareness of others and what is going on around them
- inability to make judgements
- inability to problem solve
- no independent function
- a need for help with washing and dressing and continence management.

Problems with:

- swallowing and eating
- recognising relatives, friends and familiar objects
- understanding and interpreting events
- bladder and bowel control.

Eating and drinking

An inability to swallow can increase the risk of food and drink entering the lungs rather than the stomach and this can lead to a chest infection (pneumonia).

¹It is recommended practice from the General Medical Council (GMC) that a person with end stage dementia should not be fed by tubes or drips.

Why is this?

Inserting feeding tubes or drips requires hospital admission and this can be very distressing for the person. The person may pull out the tubes and drips and the site can become infected and painful. Giving food and fluids in this way can be harmful and may not benefit the person.

For example, giving a person food or fluids via a nose or stomach tube does not:

- Stop the person from coughing or food or fluids going down into their windpipe
- Reduce the risk of chest infections
- Improve the person's ability to care for themselves
- Improve their ability to move when they previously could not
- Stop the person from losing weight
- Improve the healing of pressure sores
- Improve quality or prolong life

However, if they are unable to eat properly, sips of fluids or tastes of food can be given as a comfort measure and this can be discussed with a doctor. More information can be obtained from the Alzheimer's Society leaflets (see back of leaflet.)

Who can make medical decisions?

Where patients lack or have impaired capacity to make decisions for themselves, doctors must:

- Consider which options (including non-treatment) would be least restrictive of the patient's future choices.
- Take into account any evidence of the patient's previously expressed wishes, such as an Advance Statement or Advance Decision to refuse treatment.
- Work with those close to the patient and members of the healthcare team, to explore their views about the patient's preferences, feelings, beliefs and values and whether they consider the proposed course of action would be of overall benefit to the patient.
- Consider the views of an LPA (Lasting Power of Attorney) which allows an individual to give another person authority to make a decision on their behalf. A health and welfare LPA allows the attorney to make decisions on the patient's behalf about their health and welfare, if there comes a time when the patient is unable to make these decision for themselves. A health and welfare attorney could make decisions about where the patient lives or day-to-day care.

The Best Interests Decision and Assessment Process

Best interest decisions are made on behalf of someone who lacks the capacity to do this for themselves.

The paperwork should be completed by a healthcare professional, but with involvement of family, carers or nominated decision-makers, for example, someone with Lasting Power of Attorney (LPA) or a court appointed deputy.

In order to make a decision on behalf of someone else it is necessary to demonstrate that a person lacks capacity to make decisions and that everything possible has been done to involve them in the decision-making process.

The time to start considering this may be after a recent hospital admission or at a time when it becomes clear to you and your family what you would want to do if a similar situation arose in the future.

The first part of the Best Interest process is an 'Assessment of Capacity'.

The next part of the process maybe a 'Best Interest Meeting'. This part of the process is essential to demonstrate that full consideration has been taken into account of what the person would have wanted, should a certain situation arise.

Input from medical and nursing staff, family, carers and appointed decision makers is essential.

It may be appropriate to discuss and consider whether the person would have wanted some of the interventions outlined below.

Admission to Hospital

It is important to consider in advance whether admission to hospital and active medical treatment would be appropriate. If an unexpected health event occurs then management in hospital may be the best course of action. It may be helpful to consider a Treatment Escalation Plan (TEP) if not already in place. Please discuss with your doctor/nurse who will explain the process. ²The policy and guidance can be accessed via the Torbay & Southern Devon website.

However, for many people in the end stages of their illness, being admitted to a hospital may not be the best option.

Cardio-pulmonary resuscitation (CPR)

In patients who are generally weak, and in whom there are a number of advanced medical problems, the chance of resuscitation being successful is extremely low.

Your Involvement

The involvement of relatives, carers and friends for people with end stage dementia is invaluable and contributes to the best possible quality of life.

PALS – Patient Advice & Liaison Service.

Tel: 0800 0282037 or 01803 219700 For Patient advice and support.

Email: customerservices.tsdhct@nhs.net or pals.sdhc@nhs.net

For further information & support please contact:

Alzheimer's Society on 0300 123 2029
devon@alzheimers.org.uk

Alzheimer's Society Reference Leaflets

- Factsheet 417 Later stages of dementia
- Factsheet 511 Eating and drinking
- Factsheet 463 Advance decision
- Factsheet 460 Mental Capacity act 2005

References

¹ GMC Medical Council, End of life treatment and care: Good practice in decision-making. *Special Challenges in applying the guidance, Clinically assisted nutrition and hydration.*

² Torbay and Southern Devon Health and Care, *Treatment Escalation Plans (TEP) and resuscitation decisions records, September 2012.*

<http://www.torbaycaretrust.nhs.uk/Pages/SearchResults.aspx?s=TCT%20Internet%20Std&k=treatment%20escalation%20plans>

Please ask if you would like to receive this document in large print, Braille, on CD or in any other languages. Please contact our Patient Advice and Liaison Service.