

# End of Life Care in Dementia

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#### **Objectives**

- Understanding the decline in people with dementia
- To recognise when patients are dying
- Understanding pain in people with dementia
- To provide support and encouragement for relatives/carers of the dying patient
- Challenges in end of life care and dementia





#### A little bit about dementia



- Dementia is not a single disease, but a syndrome caused by a variety of diseases or injuries
- Symptoms are caused by structural and chemical changes in the brain, causing brain cells to die
- Its generally chronic and progressive in nature and is characterised by deterioration on cognitive function (beyond that seen in normal ageing)
- It affects memory, thinking, ability to learn new things, language etc. and is commonly accompanied or preceded by deterioration in emotional control, social behaviour or motivation and eventually affects global functioning



#### Understanding decline in dementia

#### **Stages of dementia**

1. Person with dementia becomes aware





2. Memory lapses become more obvious

3. Highly impaired



### End of Life Care for people with dementia

Emphasis on communication

Respect for the dignity of the person

Quality of life





## Recognising that death is approaching

There are symptoms of later-stage dementia that can signal that the person is reaching the final stage of their illness.

#### These include:

- Speech limited to single words or phrases that may not make sense
- Needing help with most everyday activities
- Reduced eating and difficulties swallowing
- Bowel and bladder incontinence
- Inability to walk or stand, problems sitting up and controlling the head, and becoming bed-bound.



# Recognising that death is approaching

As someone's condition worsens and they get to within a few days or hours of dying, further changes are common.

#### The person will often:

- Deteriorate more quickly than before
- Lose consciousness
- Be unable to swallow
- Become agitated or restless
- Develop a characteristic irregular breathing pattern
- Have cold hands and feet.



#### Specifically for people with dementia

- PAIN often unrecognised
- Dyspnoea difficult to recognise if not communicative
- Delirium common

- Respiratory secretions death rattle
- Distress Comfort observations



#### **Comfort Observations**

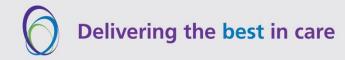
- Approximately 1/3 will not survive their hospital admission
- Often not appropriate to continue observations
- Comfort Observations should be made in consultation with the MDT

#### **For Comfort Observations:**

- Recommended twice daily observations such as respiratory rate and pulse should be continued
- Recording oxygen saturations
- Blood pressure and weight
- Medications, blood gases, blood tests and imaging
- Key symptoms patients suffer toward the end of the life are pain, breathlessness, increased respiratory secretions, agitation, nausea and vomiting.).

Comfort Care Pack should be offered to relatives

'Committing to the priorities of care' window sign





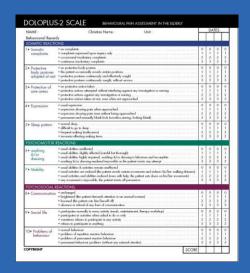


#### **Understanding pain in dementia**

Pain in advanced dementia is a common symptom but is often poorly recognised and under treated. This may be a result of poor communication, lack of recognition or misinterpretation of pain.

If a person is unable to express their pain, observational tools such as Abbey, Doloplus or DISDAT can be very useful to determine someone's level of pain, how it affects them and how well the management of that pain is working









# Supporting Carers

#### The key principles:

- Carers and the essential role they play are identified
- Greet the family and make every effort to talk to them
- Overnight stays (Breakfast, hot drinks)
- Comfort Care Packs
- Acknowledge the carers needs



#### Challenges in end of life care and dementia

- Impaired communication of need (communication should be through the use of other senses
- Difficulty in assessing pain/other symptoms
- Aggressive resistance/challenging behaviour
- Poor pain management
- Physical and mental decline
- Behavioural and psychological symptoms
- Ethical and legal issues
- Nutrition and hydration

- Diagnosing dying
- Discontinuation and conversion of medication
- Pathway drugs
- Prolonged dying phase
- Bereavement support
- Resources
- Education
- Communication skills training







# Dementia Care at UHB

See Me Care Bundle

**Dementia Friends** 

Barbara's Story



Enhancing the Healing Environment











# Any Questions?

