

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.

Abbey Pain Scale
For measurement of pain in people with dementia who cannot verbalise.

How to use scale: While observing the resident, score questions 1 to 6.
Name of resident: _____
Name and designation of person completing the scale: _____
Date: _____ Time: _____

Latest pain relief given was: _____ at _____ hrs.

Q1. Vocalisation eg. whimpering, grunting, crying Absent 0 000 1 Absent 2 000 3	Q1	<input type="checkbox"/>
Q2. Facial expression eg. looking tense, frowning, grimacing, looking frightened Absent 0 000 1 Absent 2 000 3	Q2	<input type="checkbox"/>
Q3. Change in body language eg. fidgeting, writhing, pulling part of body, withdrawing Absent 0 000 1 Absent 2 000 3	Q3	<input type="checkbox"/>
Q4. Behavioural Change eg. increased restlessness, refusing to eat, withdraws in usual pattern Absent 0 000 1 Absent 2 000 3	Q4	<input type="checkbox"/>
Q5. Physiological change eg. temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor Absent 0 000 1 Absent 2 000 3	Q5	<input type="checkbox"/>
Q6. Physical changes eg. skin tears, pressure areas, erythema, excoriations, pressure blisters Absent 0 000 1 Absent 2 000 3	Q6	<input type="checkbox"/>

Add scores for 1 - 6 and record here → Total Pain Score:

Now tick the box that matches the Total Pain Score →

Finally, tick the box which matches the type of pain →

Chronic Acute Mixed Chronic

Dementia Care Australia Pty Ltd
Website: www.dementiacare.org.au

DOLOPLUS 2 SCALE BEHAVIOURAL PAIN ASSESSMENT IN THE ELDERLY

NAME: _____ Christian Name: _____ Unit: _____

		RATES		
		0	1	2
SOMATIC REACTIONS				
1* Somatic complaints	no complaints complaint expressed upon inquiry only occasional incoherent complaints continuous incoherent complaints	0	1	2
2* Protective body postures	no protective body postures the patient occasionally reacts to pain protective postures continuously and effectively sought protective postures continuously sought without success	0	1	2
3* Protection of sore areas	no protective interventions protective actions attempted without interfering against any investigation or nursing protective actions against any investigation or nursing protective actions taken of rest, even when not approached	0	1	2
4* Expression	no expression expression during pain when approached expression during pain even without being approached persistent and usually loud vocalisation during lasting pain	0	1	2
5* Sleep pattern	normal sleep difficult to go to sleep frequent waking (intermittent) continuous sleeping waking times	0	1	2
PSYCHOSOMATICS REACTIONS				
6* Waking &/or sleeping	usual abilities unaffected usual abilities slightly affected (awake but fidgety) usual abilities highly treated, waking &/or sleeping is laboured and incoherent waking &/or sleeping reduced to possible in the patient meets any attempt	0	1	2
7* Mobility	usual abilities in motion remain unaffected usual abilities can reduce the patient search certain movement and reduce his/her walking distance usual activities and abilities reduced from both help, the patient can move on his/her own any movement is impossible, the patient needs all assistance	0	1	2
PSYCHOSOCIAL REACTIONS				
8* Communication	unchanged heightened (the patient demands attention to an unusual extent) loss of the patient can be heard all absence or total of any form of communication	0	1	2
9* Social life	participates normally in any activity (break, entertainment, therapy workshop) participates in activities when asked to do so only continues to participate in any activity absence from participation in anything	0	1	2
10* Problems of behaviour	normal behaviour presence of negative reaction behaviour presence of persistent negative behaviour persistent behaviour problems (without any external stimulus)	0	1	2

COPYRIGHT _____ SCORE:

DISDAT 1 - Dementia: Signs of Distress Behavioural Assessment This is a measure of pain.

Question	Response	Score
1. Does the person have any of the following signs of distress?	Yes/No	0/1
2. Does the person have any of the following signs of distress?	Yes/No	0/1
3. Does the person have any of the following signs of distress?	Yes/No	0/1
4. Does the person have any of the following signs of distress?	Yes/No	0/1
5. Does the person have any of the following signs of distress?	Yes/No	0/1
6. Does the person have any of the following signs of distress?	Yes/No	0/1
7. Does the person have any of the following signs of distress?	Yes/No	0/1
8. Does the person have any of the following signs of distress?	Yes/No	0/1
9. Does the person have any of the following signs of distress?	Yes/No	0/1
10. Does the person have any of the following signs of distress?	Yes/No	0/1
11. Does the person have any of the following signs of distress?	Yes/No	0/1
12. Does the person have any of the following signs of distress?	Yes/No	0/1
13. Does the person have any of the following signs of distress?	Yes/No	0/1
14. Does the person have any of the following signs of distress?	Yes/No	0/1
15. Does the person have any of the following signs of distress?	Yes/No	0/1
16. Does the person have any of the following signs of distress?	Yes/No	0/1
17. Does the person have any of the following signs of distress?	Yes/No	0/1
18. Does the person have any of the following signs of distress?	Yes/No	0/1
19. Does the person have any of the following signs of distress?	Yes/No	0/1
20. Does the person have any of the following signs of distress?	Yes/No	0/1

Total Score:



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

Queen Elizabeth Hospital Birmingham NHS
Part of University Hospitals Birmingham NHS Foundation Trust


All about me

Dear patient, relative or carer:

We are always trying to improve the care we provide to patients and aim to ensure all feel safe and cared for while in hospital. In order for us to personalise the care that we are giving to:

Name _____


It would be very helpful if you could take the time to fill in this 'All About Me' booklet. A friend or relative may complete it on your behalf and return it to the nurse in charge. If you would like to keep a copy of the completed form, the nurse in charge will be happy to copy it for you.

 Prompt pages are included to help you to complete the form and understand what information might help us provide appropriate care.

Thank you for taking the time to complete this booklet.

Yours sincerely,

Ward staff

 Dignity in Care



Dementia Care at UHB

See Me Care Bundle

Dementia Friends

Barbara's Story

Enhancing the Healing Environment



Delivering the best in care

University Hospitals
Birmingham
NHS Foundation Trust



Any Questions?



Delivering the **best** in care

University Hospitals
Birmingham **NHS**
NHS Foundation Trust