

Dementia and end of life care

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Dementia Challenge Project – achieving excellence at end of life for people with dementia 2013

- 6 nursing homes in North Hampshire
- Experiential learning model
- Identification of dementia EOLC champions in each home and small group teaching
- Reduction in EOL hospital admissions
- Increased knowledge, skills and confidence of staff

Challenges of providing high quality end of life care in care homes

- Residents are on a living dying continuum – many living with advancing incurable diseases
- Pervading culture of functional rehabilitation vs palliative care approach – striving to keep alive vs allowing natural death
- Majority of residents admitted to nursing homes will die within 2 years
- Isolation and lack of good role models, training and support around end of life care

North Hampshire Six Steps Programme - PURPOSE

- To deliver a low cost, high quality end of life care education and practice development programme, available to all care homes in North Hampshire
- To support the development of nominated staff in care homes to become End of Life Care Champions implementing organisational change utilising the Route to Success for Care Homes (National End Of Life Care Programme 2010)

North Hampshire Six Steps Programme - FUNDING

- Facilitator post is funded by NHS NHCCG
- Facilitator and programme is supported and managed by St Michael's Hospice
- No direct cost to care homes
- Indirect cost to care homes in terms of releasing staff to attend workshops

North Hampshire Six Steps

Programme – CARE HOME COMMITMENT

- Provide core group of Champions – manager or clinical lead, RN/SHCA, HCA
- Core group attend 8 half day workshops
- Home releases as many staff as possible to attend 2 whole day workshops
- Managers attend action learning sessions
- Core group complete portfolio of evidence which demonstrates delivery of care in line with the Six Steps learning outcomes.

North Hampshire Six Steps Programme - THE STEPS

1. Discussions as the end of life approaches
2. Assessment, care planning and review
3. Co-ordination of care
4. Delivery of high quality services in a care home
5. Care in the last days of life
6. Care after death

North Hampshire Six Steps Programme - 2014/15 Outcomes

Between October 2014 and June 2015

- 50% reduction in hospital as place of death
- 44% decrease in hospital admissions
- 20% increase in the number of residents returning to the homes and living for more than 1 month post discharge
- 93% residents with a DNACPR order completed at time of death or hospital admission
- 30% increase in the number of residents with an advance care plan

North Hampshire Six Steps Programme - 2014/15 Outcomes

- 68% all staff in participating homes attended 2 all day workshops
- Positive evaluation of all training
- substantial increase in knowledge, skills and confidence of the champions
- High level of family satisfaction with end of life care

Dementia and End of Life Care - What are some of the challenges?

- Recognition of dementia as a progressive, terminal disease
- Prognostication
- Advance care planning
- Tracking the journey
- Including significant others on the journey
- Symptom burden – pain, BPSD

Dementia and End of Life Care - What are some of the challenges?

- Regular medical review
- Multidisciplinary team working – care home access to consultant and palliative care advice, CPN, Physio, OT, SALT, dietician
- Communication between services
- Escalation planning and best interest decision making

Prognostication and dying trajectories

Barclay et al 2014 - 4 dying trajectories in care homes:

- ***Anticipated dying*** - recognised as approaching EOL, dying phase and death managed in the care home
- ***Unexpected dying*** – previously stable and well, illness that was not initially obviously life threatening eg urine infection
- ***Uncertain dying*** – The most complex trajectory, often resulted in hospital admission
- ***Unpredictable dying*** – previously stable and well, suffered an unexpected acute event which precipitated admission to hospital and resulted in death eg stroke, hip fracture

Prognostication and dying trajectories

Four sorts of dying (Katz et al 2003)

- General deterioration of the very old – dwindling
- Death from an acute episode eg stroke, pneumonia
- Dying from a terminal disease eg cancer, Parkinson's
- Sudden death

Prognostication and dying trajectories

Hockley et al 2010 – most care home deaths “dwindling” with bounce back episodes. Admission to hospital due to “acute event”. Sudden death not seen as part of natural dying but more acceptable to staff if DNACPR in place.

Advance care planning

- ACP enables individuals to maintain their autonomy by registering their views and concerns.
- An advanced care plan is an important tool for health care professionals to share information about an individual's wishes and preferences and inform end of life care planning and decision making
- ACP is not only about discussing care in the final stage of life, it is also an opportunity to clarify more about how the individual wants to live

Advance care planning

Difficult conversations

“What are your thoughts about the future, how do you see things going?”

“In thinking about the future, have you thought about where you would prefer to be cared for as your illness gets worse?”

“What do you want/not want around treatment and care in the future”

“Who is important in your life? What role do you want them to play as you become less well?”

“what decisions need to be made and how do you want to be involved?”

[Alzheimers.co.uk/this is me](https://www.alzheimers.co.uk/this-is-me)

Tracking the dementia journey

- Over time behavioural problems decrease, physical problems increase
- Physical frailty characterises the later stages of dementia
- Carer burden increases
- Colour coding, FAST tool

<http://geriatrics.uthsca.edu/tools/FAST.pdf>

Tracking the dementia journey – advanced dementia

- Often physical difficulties with eating and swallowing
- Aspiration pneumonia often arises from saliva not food
- Studies have shown that gastrostomy feeding is not life prolonging in advanced dementia
- Infections are common
- Poor prognostic indicators for chest infections are feeding dependency, reduced alertness, tachycardia, tachypnoea, inadequate hydration, pressure sores
- It is possible to treat pneumonia symptomatically and maintain comfort

(Pace 2011)

Tracking the dementia journey – Terminal indicators

- FAST stage 7c
- Weight loss of 10% or more over 6/12 in absence other cause
- Reduced oral intake
- Recurrent infections
- Serum albumin 25g or less
- Pressure sores
- Hip fracture

Escalation Planning

- Crucial if patient in a care home
- Best interest decision making – collaborative approach, involve carers/professionals and significant others
- Document plan
- DNACPR
- GSF/end of life register
- Ambulance anticipatory care plan

End of life care

- Symptom burden at end of life not usually high unless there is co-morbidity eg cancer
- Observational pain tools – look for trends and pattern, score on movement/care as well as rest and at different times of the day **PAINAD**
- MRI studies suggest pain perception may be increased as dementia progresses but verbalisation is reduced
- Common causes pain in dementia – back pain, joint pain, muscle spasticity, pressure sores
(Pace and Scott 2013)

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