‘Planning for the Future’
Dementia Specific Unit

Project funded by Irish Hospice Foundation
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Please don't send me away to die!
I'm not ready to die yet.
I am not afraid to die. But I don’t want to be in pain.
• Paddys Story
Aims

To develop a framework to support staff with Care Planning Discussion around End of Life issues with residents/families in Le Cheile
Project Team

Representatives from:

- Nursing specialists/manager from the areas of Dementia and Palliative Care
- Medical Specialists from the area Gerontology and Palliative Care
- Director of Nursing and Education Facilitator St Vincent’s Hospital Athy and St Brigid’s Hospice, The Curragh
- Community services
- Programme Development Manager IFH
STEP 1

Project team
Discussion & Planning

Overview of literature

Case note reviews
Staff Questionnaire
Information sessions with staff
Overview of Literature

• End of life care in dementia – problems relate to communication, symptom control and often lack of ability to make choices

• Dementia seldom recognised as a progressive/terminal illness (Ouldred and Bryant, 2008)
  Draper (2008)
  Progression varies 2 – 15 years  (Lloyd-Williams 1996)

• Small number of people with dementia referred to Specialist Palliative Care and people with dementia are less likely to be referred to palliative services despite having similar symptoms at end of life as patients with cancer
  (Carole 2010, Sampson et al 2006)
Overview of Literature

• Advanced care planning discussion can reduce the need to consult out of hours medical support, reducing the need to transfer to acute services in non emergency events

• Greater satisfaction for patient’s/ families at end of life when time is devoted to end of life discussion (Birch & Draper 2008 cited Engel et al 2006)

• Care pathways for dementia are mainly UK based, Gold Standard framework, Liverpool care pathway and UK End of Life Strategy

• IHF ‘Palliative Care for All’ document (2008) acknowledge the need to include dementia as life limiting illness
Findings from Case Notes Review

• 10 nursing/medical case notes reviewed
• Where conversations around end of life and dying were recorded it was as a result of an acute event
• In 80% of cases ‘end of life sections’ in care plans was either left blank or because of residents dementia ‘unable to verbalise’ wishes. Families not asked
• Where end of life discussion/ documentation took place they were initiated by the CNS or CNM2 who then liaised with medical officers
• Where end of life care preferences were recorded in nursing & medical notes, residents were less likely to be transferred to acute care or have unnecessary invasive procedures
Analysis Staff Questionnaire

17 questionnaires were circulated to all staff working in Le Cheile:

• All staff were happy to be involved in or initiate social conversation
• Majority of staff found it difficult to give bad/sad news
• Health care assistants felt uncomfortable asking too many questions
• Nurses claimed they found it easier to initiate conversation around end of life care with relatives rather than with the residents/patient.
However!

While staff report finding it easy to initiate conversation around end of life with a relative there was little documented evidence in care plans that any conversation took place!
Case Studies
Case Study 1.

Ann has come to your nursing home after a long stay in an acute hospital where she was admitted for treatment of a chest infection. She has arrived with a recent diagnosis of dementia. Her pre-admission assessment identified that she needs assistance x1 with activities of living and she has an MMSE of 16/30.

On conversing with Ann, she can follow most conversations and has some insight to where she is even though she remains adamant that she will be going home. Ann receives weekly visits from her 2 daughters who seem to have a limited understanding about dementia and are eager for her to receive all relevant treatment so “she can stay well”.
Questions

1. What do you find difficult/challenging with having an End Of Life Care discussions with What steps could you take to maximise the opportunity for a person with dementia to engage in EOLC discussions?

2. Within your role what people with dementia like Ann and her family?

3. What are the pros and cons in commencing EOLC discussions in the 1st week of Ann’s admission.

4. What were the barriers to this
Case Study 2

Ann has been a resident at the nursing home for 7 months and there has been a steady decline in her cognitive status. Recently, she also had a 4 day admission into an acute hospital and is currently taking another course of antibiotics.

Initially when Ann arrived into the nursing home, she reported that she wanted to go to hospital when she became acutely unwell. However, last night when a HCA was helping her into bed, she mentioned that

“I really don’t want to go back into hospital again... I’m worried, I am not getting any better...”
Questions

What would you feel is an appropriate action for the HCA?

What skills and knowledge do you feel the HCA/Staff would need to be able to meaningfully engage in this conversation with Ann?

What do we do with this information?
Discussion Group Sessions Findings

Question schedule was used to structure the discussion groups and to clarify findings from the questionnaire.

Themes from discussion groups:
1. Staff’s lack of confidence around communication on end of life issues.
2. Uncertainty around definitions of palliative care Vs end of life care.
3. Problem recognising the ‘dying phase’ of someone with dementia.
4. Uncertainty around who’s role it is to initiate the discussion on EoL.
5. Managing difficult situations.
6. Need for advise around symptom management and the need for anticipatory prescribing.
7. Advice needed on how to support relatives in their bereavement and the affect a death may have on staff.
Influencing Factors for Step 2

• People with dementia can express preferences and wishes
• Need for staff to recognise/identify what residents preferences and wishes are as early as possible ie. ‘special moments’
• Staff need to further develop their skills to improve confidence around end of life discussion with residents and their relatives
• Conversations around end of life need to be a ‘normal’ part of care and re-evaluation, involving residents and their families
STEP 2

Action Plan Developed

Importance of recognising residents ‘moments’

Staff education
- End of life module on national dementia training programme
- Final Journeys Training including communication skills
- Symptom Management guidelines

Adapting Residents care plan
- ‘End of Life Domain’ Three monthly review option

Update local end of life policy
- Visual prompt cards

Importance of recognising residents ‘moments’
Care Plan Page and Guidelines

• The healthcare team can communicate with the person with dementia at initial admission, introducing the discussion about their preferences and wishes around end of life care.
• Staff have the opportunity to discuss care options with residents and to alleviate decision making concerns during periods of acute illness.
• Supported by Guideline document and worded in a way that encourages discussion about end of life care.
• Provides means to document both formal and informal discussions around end of life care.
Symptom Management

• Develop guidelines for staff to ensure symptoms at end stage dementia are addressed effectively, thereby optimising quality of life for people with dementia as they enter the ‘dying phase’ of their illness.

• Encourages nursing and medical staff to ‘anticipate’ symptoms that may occur at end of life and prescribe accordingly and reducing out of hour referral.
What are the advantages of discussing end of life care?

• For many people in the end stages of their illness, being admitted to an acute hospital may not be the best care option (ASI UK 2012)
• In patients where there are a number of advanced medical problems, the chance of resuscitation being successful is extremely low.
• It is important to note that discussions are around ‘preferences and wishes’ and are not a legal agreement.
• If a resident is transferred to acute care from Le Cheile End of Life discussion page is included in documentation along with ‘This is me’ document
What are the advantages of discussing end of life care?

- Opportunity for the healthcare team to explore with residents their views about preferences, feelings, beliefs and values.
- Opportunity to discuss proposed course of treatments and how they would be of overall benefit for resident.
• Part of the process includes what can be referred to as 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.
Evaluation

• 100% of residents notes have relevant information on End of life domain
• Majority of staff had taken responsibility for writing in End of Life Domain,
• Two staff who had not initiated end of life discussion or written in care notes had not completed any training around end of life care
• Discrepancies found between residents care plans and medical notes, leading to uncertainty in emergency situations
Phase 2

• Draft copy of medical page to address discrepancies between nursing and medical documentation
• Complete annual care plan audit on End of Life domain in Le Cheile.
• End of life committee formed
• Introduced documents developed from phase 1 to other wards in hospital
• Developing a palliative care dementia specific bed within an expanded Le Cheile
• Continue developing End of Life care philosophy for people with dementia with support from Irish Hospice Foundation and Hospice Friendly Hospice programme.
Conclusion

• End of life discussion for people with dementia can be challenging for staff
• Importance of communication skills for staff
• Staff need education to build confidence to initiate end of life discussions
• Improved documentation will improve quality of care for residents around end of life and reduce unnecessary invasive procedures and transfers
• Need to Keep End of life Care a priority when planning care