End of Life Care in Dementia

Basic overview of some of the practice issues

Aims of the session

- Overview of key documents and policies related to Dementia End of Life Care.
- Overview of End of Life core competences and 7 principles
- Explore some of life and health related issues related to EOLC in Dementia including the “Gold standard”
- Provide basic communication some basic tips for carers
- Advanced care planning in EOLC in Dementia

End of Life Care (dementia)

Some Key Documents

- Commissioning framework End of Life care (2010)
- Common core competences and principles for health and social care workers working with adults at the end of life. (2010)
- My life until the end :dying well with dementia Alzheimer’s society (2012)
The Alzheimer’s report “Living and Dying in Dementia” (2014) identified 3 themes or barriers to care.

**Intervention and planning**
- Lack of timely and appropriate diagnosis
- Lack of recognition of dementia as a terminal condition
- Failure to identify dementia as a cause of death
- Ineffective advance care planning

Alzheimer’s Society (2014)

**inequality of access**
- Access to palliative care
- Access to hospice care
- Access to funding
- Discrimination

Alzheimer’s Society (2014)
Inconsistency in care standards in hospitals
- Inappropriate hospital admissions
- Lack of continuity of care
- Inappropriate interventions
- Failure to adapt practice to reflect the different nature of dementia
- Lack of support for carers

The Department of Health (2008) suggests that, for many, a good death would involve being treated as an individual, with dignity and respect, without pain and other symptoms, in familiar surroundings and in the company of close family and friends.

Too often, however, people with dementia receive undignified treatment and are ending their lives in pain (Alzheimer’s Society 2012, Health Service Ombudsman, 2011, Commission on Dignity in Care for Older People, 2012, Royal College of Psychiatrists 2011) and partnership between dementia care and palliative care are undeveloped (NCPC, 2009).

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People with dementia may not be referred for specialist end of life care or receive inappropriate treatment.

People with dementia have the same right to a good death as people with other health conditions.
1. Choices and priorities of the individual are at the centre of planning and delivery.

2. Effective, straightforward, sensitive and open communication between individuals, families, friends and workers underpins all planning and activity. Communication reflects an understanding of the significance of each individual’s beliefs and needs.

3. Delivery through close multidisciplinary and interagency working.

4. Individuals, families and friends are well informed about the range of options and resources available to them to be involved with care planning.

5. Care is delivered in a sensitive, person-centred way, taking account of circumstances, wishes and priorities of the individual, family and friends.

6. Care and support are available to anyone affected by the end of life and death of an individual.

7. Workers are supported to develop knowledge, skills and attitudes. Workers take responsibility for, and recognise the importance of, their continuing professional development.

Stage 1 (Early Dementia): Dignity through autonomy: Independence

- Not a trivial stage
- Dignity is much more difficult in dementia
- The individual often cannot cooperate in the care.
- Dignity for all involved in a dementia situation – the primacy of the person with dementia and also the carers
- Person may or may not have had a dementia diagnosis but be exhibiting symptoms
Diagnosis of Dementia is key to best quality of future care

- Carers in this stage need support – acknowledging the burden on the family/carers
- Setting up plans for the future – help with food preparation, personal hygiene; PPC; end of life considerations; Do Not Attempt Resuscitation Order
- Important to know who are the decision makers – enduring power of attorney and legal guardian
- Mental capacity assessment – may be fluctuating
- Needs constant monitoring and readjustment

Dementia will progress and when that happens someone needs to step in

- Keeping the person at home; in their comfort zone – may be periods of respite, either at home or another facility
- Optimal management of coexisting conditions eg vascular disease; diabetes;
- There are medications that can slow the decline – limited effect – at best 6 months improvement in 30% of people
- Hospitalisation needs careful planning to minimise potential delirium or of the person becoming upset or agitated

STAGE 2 – GOAL HERE IS SAFETY

Stage 2 occurs gradually

- When family/carers cannot cope with the person at home any longer – may need a roster system or consider care homes
- Safety becomes difficult to maintain eg. Fire in the house, a sore that isn’t healing,
- Carers family begins to identify the carer is suffering as a result of caring
- Not all about pristine medical management of comorbidities
- It is about finding out what it is that gives the person happiness and enjoyment
- This may be different to what they enjoyed before
STAGE 3 – COMFORT – PALLIATIVE CARE AND SYMPTOM CONTROL

- People in stage 3 may be mobile or not
- These people are our most frail and vulnerable members of society
- The fundamentals of caring are paramount – simple comfort measures - sitting with the person, stroking their hand, listening to music, sunlight as well as everyday hygiene measures
- They are no longer as they were – they may be agitated and tormented
- Drugs work poorly – but we owe them the best symptom control

We need to be prepared
- Issues of consent are very pertinent to this group of people
- Interactions between drugs and side effects eg opiates, anti cholinergic medication (Cogentin) for parkinsons
- Anticipatory prescribing with care for anticipated symptoms
- Symptoms common are psychotic symptoms – aggression, agitation, confusion
- Are they really that distressed by their symptoms

Anti psychotic medication have modest benefit and many side effects
- Sedative drugs eg benzodiazepines have significant side effects and can cause falls
- As the end of life approaches – stopping unnecessary medication/treatments eg cholesterol lowering drugs; other conditions that may occur eg a cancer; pneumonia
- Non drug treatments – physical touch; interaction with pets; music; environmental factors
Some of the health issues seen in later stages of dementia

- Loss of mobility
- Eating and weight loss
- Problems with continence
- Unusual behaviour
- Immobility
- Side-effects of medication
- Illness and discomfort
- Medication
- What care or treatment may be offered?

What is likely to cause the person with dementia eventual death?

- Pneumonia is listed as the ultimate cause of death in up to two-thirds of people with dementia.
- Third of people at any one time will be in the later stages of dementia.
- Although dementia is a life-shortening illness, another condition or illness (such as pneumonia - an infection in the lung) may actually cause a person’s death. The person’s ability to cope with infections and other physical problems will be impaired due to the progression of the disease

3 ways

In some people no specific cause of death is found, other than dementia.

Summary

1. Death caused by another medical condition
2. Interplay between dementia and another condition
3. End stage dementia

- Evidence suggests that access to services is inequitable
Difficult to predict nature and timing of death

End of Life care in dementia can be considered as a broad approach over many years to address needs

Inequitable access to services and appropriate treatment

Challenges we may face

- Unable to walk
- Urinary and faecal incontinence
- No consistently meaningful communication
- Unable to dress without assistance
- Barthel score less than 3
- Reduced ability to perform activities of daily living
- Plus any of the following: 10% weight loss in previous six months without other causes, pyelonephritis of UTI, Serum Albumin 25g/L

1. Reduced eating and swallowing

Dementia Prognosis indicator Guidance Gold standard 2005

Recognising when someone is reaching the end of life

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

(Alzheimer’s Society 2014)
Communication some basic tips for carers

- Non-verbal communication from you, through gestures, body language, facial expression and touch, can help.
- Use appropriate physical contact such as holding hands or a hug to reassure the person that you are there for them.
- Take your time and look for non-verbal signals from the person with dementia.
- Continue talking to the person, even if you don’t think they can follow what you are saying. They will understand at some level and may respond to the tone of your voice even if the factual content is lost.

Planning

- Making decisions - e.g. DNR, choice of where, Advance statements etc.
- Pain - Recognition
- food and fluids
- Infections - antibiotics use?
- Psychological, social and spiritual needs
- Place of death
- Support for carers, family and close friends
- After death

Questions to consider

- At what point should end of life services be available to service users and their families?
- What sort of assessments should we use?
In summary, the Alzheimer Society advocates that good quality end of life care should consider:

- Advance planning for end of life care
- Improved training for health and social care professionals
- Focus on quality of life, rather than length of life, in the final stages of dementia
- Improved emotional and spiritual support
- Improved planning and co-ordination of care.
- Implement the recommendations of the Leadership Alliance for the Care of Dying People
- Assisted dying!!!

References:

Neuberger (2013), More Care, Less Pathway: independent review of the Liverpool Care Pathway.