

END OF LIFE CARE FOR PEOPLE WITH DEMENTIA

Applying the palliative approach to dementia care can assist in the appropriate identification of the unmet needs of people with dementia, whilst also promoting a continuum of care that focuses on quality of life and values the individuality of the person.

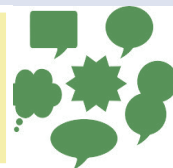
WHY IS IT SO IMPORTANT?

1. People with dementia are a vulnerable group who are at high risk of receiving poor end-of-life care (Sampson et al., 2006).
2. Due to the complex nature of dementia, people with it can be at risk of poor symptom management and of the inappropriate use of aggressive treatment (Mitchell et al., 2004).
3. Internationally, there have been many calls for improvements in the end-of-life care for people with dementia (Robinson et al., 2005).
4. People with dementia have specific end-of-life care needs. These needs should be met through clear communication and through collaborative work (IHF & ASI, 2012)
5. It is argued that the end-of-life care of these people should extend beyond symptom control so as to encompass their psychological and spiritual needs (Bayer, 2006).

GOOD END OF LIFE CARE FOR PEOPLE WITH DEMENTIA

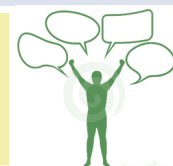
OPEN THE DIALOGUE ON END OF LIFE CARE

Initiating discussions on end-of-life care allows the person to take a lead role in determining his/her wishes. Family can also provide valuable information and help to determine the person's preferences on their future care.



DETERMINE THE PERSON'S PREFERENCES

Enquire if the person has completed an Advanced Care Plan or if the nursing home has recorded the person's preferences. Explore with family and friends if the person has previously expressed wishes on their future care.



CREATIVE WAYS TO COMMUNICATE

Remember that, as this condition progresses, people with dementia may communicate their care needs through changes in their behaviour, through visual cues, and may also have occasional lucid moments when they can articulate their needs verbally.



GOOD SYMPTOM MANAGEMENT

People with advanced dementia maybe unable to verbally communicate their pain and discomfort so symptoms assessments should involve close observations. Referral to specialist teams could be sought if there is difficulty in effectively alleviating the person's symptoms.



MEETING THE PALLIATIVE NEEDS OF PEOPLE WITH DEMENTIA — THE ROLE OF THE MULTIDISCIPLINARY TEAM —

CARE FOCUSES ON QUALITY OF LIFE

Routine tests and burdensome interventions should only be completed if they will benefit the person's overall wellbeing.

UNNECESSARY HOSPITAL ADMISSIONS

People with dementia can deteriorate when they move to an unfamiliar environment. Unnecessary hospital admissions can be avoided through advanced care planning and liaison with the medical team.

CONTINUUM OF END OF LIFE CARE

When a person with dementia has to move between care settings, make sure that accompanying documentation clearly explains the person's end of life preferences.

DIGNITY OF CARE AT END OF LIFE

Good end-of-life care is about ensuring the person's physical, spiritual and emotional wishes and preferences are met right to the end. These can be met through sensory means (touch, smells, music, photos) as well as through established medical interventions.

END OF LIFE CARE FOR PEOPLE WITH DEMENTIA

"He was very distressed in hospital ... he didn't understand what was happening to him and they didn't know how to help him"

- Carer

"We were never asked what his wishes might have been"

- Carer

"Every time he went into hospital he deteriorated."

- Carer

"Need to change approach ... death is seen as a failure. At the end somebody panics and the patient is sent to hospital"

- General Practitioner

"Patients with dementia have such highly intensive needs."

- Acute nursing staff

"If the death goes well it is a privilege to be involved."

- Care home manager

Quotes from Marie Curie Cancer Care (2009)

REFERENCES

Bayer, A. (2006) **Death with Dementia: The Need for Better Care** *Age & Ageing*, 35 (2) p. 101-102

IHF & ASI. Irish Hospice Foundation & Alzheimer's Society of Ireland (2012) **Building consensus for the future: report of the feasibility study on palliative care for people with dementia**. Dublin, Irish Hospice Foundation

Marie Curie Cancer Care (2009) **End of life care for people with dementia report** (2009) Available at <http://www.mariecurie.org.uk/Documents/HEALTHCARE-PROFESSIONALS/Innovation/project-report-0210.pdf> (9/7/2013)

Mitchell, S., Kiely, D. & Hamel, M (2004) **Dying With Advanced Dementia in the Nursing Home** *Archives of International Medicine*, 164 (9) p. 321-326

Robinson, L., Hughes, J., Daley, S., Keady, J., Ballard, C. & Volicer, L. (2005) **End-of-life care and dementia** *Reviews in Clinical Gerontology*, 15 (2) p. 135-48

Sampson, E., Gould, V., Lee, D. & Blanchard, M. (2006) **Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study**. *Age and Ageing* 35, 187-189.

KEY DOCUMENTS & RESOURCES

Opening Conversations report (2011)

http://www.alzheimer.ie/Alzheimer/media/SiteMedia/PDF%27s/Research/Opening-Conversations_2011.pdf?ext=.pdf

Planning for the Future Report (2013)

<http://hospicefoundation.ie/wp-content/uploads/2013/09/Final-Report.pdf>

End of life care for people with dementia report (2009)

<http://www.mariecurie.org.uk/Documents/HEALTHCARE-PROFESSIONALS/Innovation/project-report-0210.pdf>

Care towards the End of Life for People with Dementia: An Online Resource Guide (2010)

http://www.opaal.org.uk/Libraries/Local/1013/Docs/Dementia_resource___final___20101025.pdf

Guidance in completing the planning for end of life care form (2013)

<http://hospicefoundation.ie/what-we-do/palliative-care-for-all/dementia/introduction-to-dementia-palliative-care-2/>

