



# PATIENT SAFETY TOOL BOX TALKS®

## EFFECTIVE CARE & SUPPORT

### END OF LIFE CARE PEOPLE WITH DEMENTIA



v1.0

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.

### Core Values for Good End of Life Care

#### 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 this condition, people with dementia can suffer with poor symptom management and 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 which needs to be met through a process of clear communication and collaborative work (IHF & ASI, 2012)
5. It is argued that the end-of-life care of these people should extend beyond symptom control to encompass their psychological and spiritual needs (Bayer, 2006).

#### 1. 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 in helping to determine the person's preferences on their future care



#### 2. 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 the person's previously expressed wishes on their future care with family and friends



#### 3. CREATIVE WAYS TO COMMUNICATE.

People with dementia can struggle to verbally communicate so it is important to closely observe their behaviour and remain vigil for lucid moments when the person can communicate their needs and preferences.



#### 4. GOOD SYMPTOMS MANAGEMENT.

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



### ROLE OF MULTIDISCIPLINARY TEAM IN MEETING THE PALLIATIVE NEEDS OF PEOPLE WITH DEMENTIA

#### CARE FOCUSES ON QUALITY OF LIFE

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

#### AVOID UNNECESSARY HOSPITAL ADMISSIONS

People with dementia can decline when moving to an unfamiliar environment. This admissions can be avoided through advanced care planning & liaison with the medical team.

#### CONTINUUM OF END OF LIFE CARE

Ensure documentation clearly explains the person's end of life preferences and is moved with the person as they transition between care settings.

#### PROVIDE DIGNITY OF CARE

A range of different mediums can be used to meet the often unmet needs of people with dementia (i.e. touch, smells, meaningful music, photos)

“Need to change approach ..... death is seen as a failure. At the end somebody panics and the patient is sent to hospital”  
-General practitioner

“If the death goes well it is a privilege to be involved.”  
- Care home manager

“Every time he went into hospital he deteriorated.” - Carer

“Patients with dementia have such high intensive needs.”  
-Acute nursing staff

“We were never asked what his wishes might have been”. – Carer

“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

“My mother did not have spiritual needs in the last six months. My mother had nothing.”  
- Carer

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](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/what-we-do/palliative-care-for-all/dementia/introduction-to-dementia-palliative-care-2/>
- 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](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/>