

# Top Tips for Supporting PWD and their Families through Terminal Illness

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12/9/2018

# Dementia in Ireland

- 29% (estimate) of the typical patient population in our general hospitals
- 34% of people with Dementia live in Nursing Homes (70% of NH population)
- Large % of patients accessing generic homecare services have a diagnosis of dementia (O'Brien 2017 study found 37% NDS Review)
- Currently 55,000 people with dementia – set to double within 20 years and almost triple within 30 year to 152,000 (Nat. Dementia Strategy Review, 2018)

# Dementia – Facts and Features

- Dementia is a life-limiting condition currently without cure (Kydd, A. & Sharpe, B. 2015)
- Dementia is 7<sup>th</sup> leading cause of death globally
- 5<sup>th</sup> leading cause in upper-middle income
- 3rd leading cause in high income countries (WHO, 2012)
- Can be helpful to think in terms of stages:
  - Early
  - Moderate
  - Late (advanced / severe)

# Definitions of Dementia

- Dementia is an organic, acquired syndrome characterised by a permanent impairment of certain cognitive functions including memory. There are usually psychiatric, personality and behavioural symptoms present (Rexach, L. 2012)
- 'A common or persistent disorder of the mental processes caused by brain disease or injury and marked by memory disorders, personality changes and impaired reasoning'  
[en.oxforddictionaries.com](http://en.oxforddictionaries.com)
- 'A usually progressive condition (such as Alzheimers Disease) marked by the development of multiple cognitive deficits (such as memory impairment, aphasia, and the inability to plan and initiate complex behaviour)  
[www.merriman-webster.com](http://www.merriman-webster.com)

# Person centred approach to Dementia

- Challenges the traditional medical model of dementia which focuses on disease
- Term 'person-centred' coined by Tom Kitwood
- Defined Dementia as 'the interplay between neurological impairment and psychosocial factors, health, individual psychology and the environment, with particular emphasis on social context.
- Personhood is a central idea in person-centred care

“a standing or a status that is bestowed on one human being by another in the context of relationship and social being (Kitwood, 1997, p8)

# Person centred care - features

- Challenges the idea that cognitive ability underpins personhood
- Being human is much more than memory and should not be viewed only in terms of cognitive abilities.
- The environment has as much effect on the brain as the brain has on the person's abilities.
- Others have an essential role in activating and maintaining the sense of self in PWD
- Supporting a sense of self and personhood through relationship-based care and services and providing individualised activities and meaningful engagement
- Not them who are 'damaged' and we who are whole...Brings awareness to the fact that everybody carries damage in some way, eg. fears, uncertainties, insensitivities, etc.

# Person Centred Care and Policy

- “Each person with Dementia is **unique** and has a different range of abilities and needs for support...Good dementia care involves using this information to develop “**person-centred**” care...” **Guidance on Dementia Care for Designated Centres for Older People HIQA, 2016, P8**
- “...the dual and overarching principles of personhood and citizenship...**valued independent citizens** who, **along with their carers**, have the right to be included as active citizens...” **NDS, 2014**
- ‘the principles of **person-centred care** underpin good practice in dementia care... (and recognises) The human value of people living with dementia, and **their families and carers**’ Quality Standard for supporting people to live well with Dementia (NICE Quality Standard 30). London, **NICE, 2013**

# Palliative Approach to Care of PWD

- “Palliative Care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness...”WHO, 2002
- Better understanding
- Definition of the Family Definition
- “All those in a loving relationship with the person who is dying, the people who provide care and support, regardless of blood or legal ties”  
(Lattanzi-Licht et al, 1998)

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# Challenges for the family

- Caring for the PWD can be physically and mentally exhausting for families.
- Carers can experience prolonged loss / similar to grieving, eg. jolt of grief, anticipatory grief

# Caring for Families - Top Tips

- Communicate positive beliefs about caring. Care-giving may enhance self-esteem and sense of achievement from managing the multiple roles associated with caring (Bellin, M. & Fauri, P., 2006)
- Normalise and bring into awareness difficult feelings around transitioning (can reduce risk of removing PWD from place of care)
- Bringing awareness to their own needs can be helpful, ie. offer support, signpost resources which can help with putting plans in place to address personal needs.

# Caring for Families - Top Tips

- Provide opportunities for physical contact / care if appropriate / desired
- Encourage and find new ways to engage and spend time with loved one
- Provide timely and straightforward information and a family receptive environment(Bellin, M. & Fauri, D. 2006), within the context of family readiness
- Let families know you are comfortable discussing death and dying

# Caring for PWD –Top Tips

- Holistic perspective on patient behaviour and experience
- Individualised care plans
- Life-Story Work

“Involves people with dementia (and / or their families and care workers) recording aspects of their past and present lives, either for personal use or to improve care” (Life Story Work in Dementia Care, University of York, 2015)

# End of Life Care Planning

- Whilst living well with dementia is an important message, planning for advanced dementia and dying is equally important.
- Not always recognised as a life-limiting condition
- Aim for end of life care planning ASAP (1 in 12 PWD admitted to acute hospitals will die during admission).
- Early assessment and documentation of a PWD EOL care needs and preferences is important

# EOL Planning Features and Benefits

- Aggressive medical care with advanced dementia has been associated with poorer outcomes for both patients and families (NDS, 2014)
- Palliative approach associated with:
  - Structured time for communication
  - more EOL planning
  - better symptom management
- Reassurance that comfort can be targeted when treatment is ineffective
- greater family satisfaction with EOL care
- Less aggressive treatments at EOL

# Final Word

- As patients approach the EOL, families will often relate to the dying process as both difficult and valuable
- PCC with structured time for communication, timely EOL care planning and follow up support for families leads to higher satisfaction rates for families (Lattanzi-Licht et al., 1998)

# Training Programmes and Resources

- [www.understandingtogether.ie](http://www.understandingtogether.ie)
- [dementiapathways.ie](http://dementiapathways.ie)
- Addressing the Palliative Care Needs of People with Dementia IHF (Resource Pack for Staff)
- Charter of Rights of People with Dementia (Alzheimer's Society of Ireland 2016)
- My LifeStory Passport (Dementia UK)

# References

## Books and Journals

- Lattanzi-Licht, Mahoney, and Miller (1998) *In Pursuit of a Peaceful Death*, New York, Fireside Books.
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- Rexach, L. (2012) Palliative Care in Dementia *European Geriatric Medicine* 3, pp 131-140
- Kitwood, T. (1997) *Dementia Reconsidered: the Person Comes First*, Open University Press

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## Reports and Guidelines

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- Mid-Term Review of the Implementation of the National Dementia Strategy (2018) The National Dementia Office & Dept. of Health
- Dementia: a public health priority (2012) World Health Organisation and Alzheimer's Disease International
- Guidance on Dementia Care for Designated Centres for Older People (2016) HIQA
- NICE guideline (NG97) (2018) Dementia: assessment, management and support for people living with dementia and their carers.