Palliative Care for people with an intellectual disability and dementia

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CNS Dementia
Daughters of Charity Disability Support Services
The prevalence of Alzheimer’s type dementia in persons with Down syndrome exceeds that of the general population (WHO 2012)

People with DS are ageing and living longer

Mean age of onset is 54 years (McCarron et al)
Risk trajectory according to age
Case Study 1
1998

Ann, 51 years, cognitive decline but no diagnosis of dementia.

- Ann was hospitalised on numerous occasions with pneumonia and seizure activity.
- Aggressive treatments were pursued including PEG.
- Poor staff and family support.
- Ann passed away in acute setting.
- No EOL care plan.
- Lack of support for Ann, her family and her carer’s.
“We did the best we could with what we knew, when we knew better, we did better”

-Maya Angelou
Daughters of Charity Service: A Strategic Challenge

• Changing Demographics

• Ageing population with Down syndrome

• Challenges to the current service model with a need to restructure residential and day programs

• A need to up-skill staff at all levels in the organisation to respond to changing needs
Vision for care and support for persons with dementia at the Daughters of Charity Service

- That persons at risk of dementia would be diagnosed early and that early intervention including personalised supports and a capable and trained workforce would improve the quality of life and death for persons with dementia;

............additionally and that each person would be supported to live in the home or community of their choosing for as long as possible.
Strategic Plan and components of dementia specific service

- Memory clinic
- Clinical support team
- Partnership with relevant generic dementia and palliative care services
- Training and education programs for staff, peers and family
- Respite and day programs
- Research to guide practice and policy
- Dementia specific homes
The Daughters of Charity Service has responded to the challenges posed for people with dementia by designing and developing two specialist dementia care homes:

- **Willow View**; an eight bedded home supports persons with mid-stage dementia where they can no longer be supported in their existing home setting.

- **Meadow View**; a six bedded home providing high quality nursing and palliative care.
Moving Ideas into Action:
A Dementia Specific Home
Care Issues

- Epilepsy with up to 90% of people with DS and Alzheimer’s dementia developing seizure activity
- Pain Recognition and management
- Nutrition and hydration
- Infections
- Resuscitation
- Care setting and transfer issues
- Staff knowledge base/confidence
Decline in Cognitive and Functional Assessment Scores (McCarron et al 2012)

* Higher scores represent decline
End of Life Care: Ethical Framework to guide decision making
Decision making and End of Life Care

• Determining what is in the ‘best interest’ of the person in light of the terminal nature of dementia.

• Establishing the intent of treatment and the potential for beneficial outcomes vs. burden.

• Recognizing that care decisions are best determined by care teams when they reflect the person’s wishes, and family/friend input.
Case study 2
2014

Mary received a diagnosis of dementia aged 51 years

Mary supported through MDT team through a strengths based approach

Family supported through diagnosis and educated through continuum of disease process. Rapport and trust built between family and MDT over the years.

Mary passed away peacefully in her home aged 60 years surrounded by family and friends

Staff trained in all aspects of good dementia care

Established supportive relationship with local hospice and palliative care teams

Detailed EoL care plan in place. Symptom management including recognition and management of pain.

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Developing standards for care

Standard 1:
Appropriately Trained Staff and Service Development

People with dementia receive care and support from staff with the prerequisite knowledge and skills to perform their role effectively.

Standard 2:
Memory Assessment Service

All people with intellectual disability have access to a memory assessment service, including screening, dementia assessment and diagnosis in persons with intellectual disability.

Supporting Persons with Intellectual Disability and Dementia: Quality Dementia Care Standards
A Guide to Practise
McGarrigle, M & Flahy, E. 2010

Standard 3:
Communication and Behaviour

The personhood and well-being of the person is maintained through effective communication approaches.

Standard 4:

Standard 5:
Promoting Well-Being and Social Connectedness

Each person with dementia is supported to maintain relationships with those who are important to them in their family, friendship, and local community.

Standard 6:
Supporting Persons with Advanced Dementia: Addressing Palliative and End-of-Life Care Needs

Each person with dementia is encouraged and supported by staff to participate in their own personal care at whatever level they are capable of. The person’s preferences, privacy, dignity, and well-being are key principles which underpin all care activities.
I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel.

-Maya Angelou