PROVIDING PALLIATIVE CARE IN RESIDENTIAL DISABILITY SERVICES: PANDDA CONFERENCE 2014
Research widely recognises poorer health outcomes for people with disability; this is compounded in the presence of DD. People with disability are living longer but with more chronic health issues. May experience the issues of aging earlier and in addition to lifelong illness and disability.

50% of carer support is currently provided in the family home. Productivity Commission report 2011.

As carers and partners age and are no longer be able to support this cohort in family homes, support will shift to residential services.
Palliative and end of life care philosophies support a person’s right to die in their home or place of choice. Palliative care research internationally shows 90% of people would prefer to die in their own homes. Department of Human Services Victoria supports this right for residents of disability services.

Health policy both state and federal plans for and resources the support of palliative and end of life care in the residential aged care sector but for the most part does not recognise the same resource need within the disability sector.
THE IDENTIFIED ISSUES WITH PROVIDING PALLIATIVE CARE IN DISABILITY SERVICES

- Started with case study review of the experiences of 12 clients and the staff teams who provided palliative and end of life care: Issues identified:
  1. Who is making the decision about palliative care being the most appropriate pathway and their capacity/right to make this decision.
  2. The skills and knowledge of the staff group supporting a person who is receiving palliative and end of life care.
  3. The diversity of client cohort in services where palliative and end of life care may be offered.
  4. What happens after a person has died.
Legal documentation is complex—it is difficult to understand who completes the documents and where different documents have relevance.

Some disability services hold a position that all clients WILL be resuscitated despite legal documents stating wishes of the person/family to the contrary.

Medical power of attorney and Guardians—who is eligible to make decisions where a person cannot?

The person with no one to make this decision—the role of Office of the Public Advocate

Medically initiated statements DNR—the burden and futility of treatment/the use of resources/measures of quality of life

When advance care planning and palliative care are refused
DHS policy outlines the following:

1. “Residential staff may not be part of a discussion to refuse treatment” *(Residential Services Practice Manual 3rd edition)*

However:
- Staff have a role in supporting clients at an appointment and aiding discussion and understanding between the doctor and client.

2. Power to withdraw or withhold treatment rests with MPA or the treating doctor.

However:
- Doctors seek staff input and guidance where there is no NOK to help make this decision.

DHS policy documents advocate future needs planning as soon as a life threatening illness diagnosis is made. It does not define “life threatening illness” and gives no guidance on how this planning should occur.

*Disability Residential Services Palliative Care Guide (2009)*
Communication:

• Staff have difficulty speaking about death and dying on a day to day basis *(Forrester-Jones R., 2012)*

• When there is bad news-research has produced a model for this-Irene Tuffrey Wijne-breaks down this process into sequential steps.

• Communication as it relates to informed consent-the right to know. When families and care teams disagree.

Competency and capacity-capacity may inform competency and may be scaffolded.

• Communicating as part of a shared care team- meta language and understanding written and verbal information about what is happening and what is planned.
WHY IS TALKING ABOUT DYING AND DEATH SO IMPORTANT?

• Explains loss and the disappearance of friends and family. (Forrester-Jones R., 2012)

• Adds to understanding when this conversation becomes relevant for the individual

• If palliative and end of life care is to routinely occur in disability homes, death and dying needs (within the limits of each person’s capacity to comprehend) to be part of understanding for residents.

• What happens to treasured possessions

• Understanding and coping with when the next person moves into your friends space
HOW STAFF FEEL ABOUT BEING ASKED TO PROVIDE END OF LIFE CARE FOR CLIENTS

This impacted on by:

- Duration of the relationship for the staff and client
- An individual’s awareness of what is to occur
- Todd/Weise et al. studies: experiences of disability staff providing end of life care in disability services.
  - No expectation of this role at employment
  - Experience of shock when seeing death for the first time
  - Valued the experience and the contribution they could make
  - Felt fearful and that they had failed if the client did not die at home because their needs could not be met.

“The way individuals treat illness and death is heavily influenced by culture and ethnicity but also historical and socio-political contexts.” Dr Chris Atmore, Dr Charin Naksook, Respecting patient choices.
THE CLINICAL SKILLS DISABILITY STAFF NEED.

- Clinical assessment of wellbeing and capacity to identify when the person is experiencing deteriorating health
- Pain management including complex medication regimes - the use of morphine
- Medical language to communicate the person’s condition, support needs and response to treatment across care team members.
- Understanding of the normal dying process
The palliative care services we have engaged with do not understand:

- There is not nursing staff in disability services
- The disability staff have no/limited training in palliative care
- The staff do not understand death and dying
- The scope of medication practice for DSW
RISKS - GRIEF AND BEREAVEMENT

- Staff have to cope with their own grief but also support other clients and their families and the person's family. (this is tasking they take on themselves)
- A central element of Palliative Care is the support of the primary carer. This involves an assessment of their risk of extended grief.
- Community palliative care teams do no have the capacity to do this for teams of carers in disability services.
- Counselling is offered at the time of the death
- We do not track the experience of staff who lose more than 1 client in a short space of time.
- The risk to staff is not identified or measured.
DIVERSE SERVICE MODELS

- Services with residents with high and complex health needs—these services often do not have the capacity to accommodate the extra workload involved in the care of a dying person.

- Behaviours houses—cannot often not accommodate changes of routine of the increased need for multiple external agencies to access a services. The distress of staff impacts on client behaviours.

- Some services have no active night to monitor the person’s needs overnight.
WHAT WE KNOW FROM THE RESIDENTIAL AGED CARE EXPERIENCE

- Training staff in clinical skills and a palliative care model does help but it needs to be a cultural shift to recognise and accommodate the changed and increased needs of a person who is dying.
- Staff need extended support and debriefing during provision of care and after the person has died.
- This includes support with the grief and bereavement for other residents.
In the broader community 90% of people wish to die in their own home
20% achieve this goal.

How do you measure success in the provision of palliative and end of life care?
Does it relate just to the person’s outcomes or more broadly to include the outcome for staff and other residents?
How do staff personally measure success?
DISABILITY SERVICES AS PLACES OF DEATH AND DYING

- Memorialising and remembering friends this is tricky
- The service with 5 plaques on the wall at the front of the house to remember past friends
- Photos around my home of people I do not know
- How do we do this without making these homes places of death?
LEARNINGS FROM CASE STUDIES.

Disability nurse consultants function to facilitate this process. Our role includes:

1. Facilitating understanding and management of Limitation of Treatment documents. PC complete these.
2. Orientating care teams to the roles and capacities of each other.
3. Identifying tipping points where the client can no longer be supported at the service. This may relate to client’s unmet needs, staff capacity, disruption to the other clients.
4. Ensuring an identified destination if the client has to be moved—hospice.
5. Outlining the role of the coroner where this may apply.
6. Ensuring the service staff understand the death and dying process.
7. Medicating medication management.
8. Ensuring organisations staff assist service is engaged for staff.
REFERENCES


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