TASMANIAN
HEALTH
SERVICE

One short story, one big question;

How do we provide quality palliative care for those living with disability in the group home setting ?

Sarah Coulson Clinical Nurse Consultant
Specialist Palliative Care Service – North

Tasmanian
Government

The context

People with severe intellectual disability;

- increasingly faced with age related comorbid conditions
- ‘Group homes’ predominant model of care
- Often highly dependant of others for communication and needs
- Mixed interactions with healthcare sector
- Low referral rates barrier to collaborative relationships
- Often no end of life care planning
- positive parallels between disability and palliative care ethos

Read, S 2012, Stein, G 2008, Tuffrey-Wijne, I 2012,

A Short Story

- referral from GP
- Woman in early 40's (Lucy)
- Progressive chronic disease with background of severe congenital disability, poor response to pharmacological Tx
- Long term resident of group home (>20 yrs)
- Symptoms – breathlessness, intermittent resp. distress with associated panic, peripheral oedema, increased fatigue, loss of appetite
- Now cared for 24hrs in recliner chair
- Rapidly reducing functional status, very difficult to meet care needs safely (AKPS 30, Phase 2).

'This is Lucy's home, she is happiest here and we want her to die here, so how do <u>we</u> do this?'

The Challenges

- Unfamiliar environment
- Location (EOLC in a communal space?)
- Equipment needs
- Symptom assessment (what are our measures?)
- Drugs (storage and administration)
- Organisational policy for unwell patients
- Carers and other staff needs, past experiences and expectations
- Structure of staff rostering, normal routine of the home
- Other residents and their families

Building trust, respect and capacity (quickly)

Support session for carers (and education for me)

- Introduction to the palliative approach
- Focus on quality / normalising
- Explored carers needs, strengths, own experiences and health literacy
- Loss and grief
- Family needs and role
- Other residents communication, safety and needs

Our solutions

- Joint organisational support
- GP support

for bed rails, a drug chart, consent not to transfer to hospital and agreement to provide a death certificate

- A handbag! (plus a quote for a locked box)
- A phone tree
- Changes to the staff roster (utilise community nurses to reduce cost, provide additional support)
- Manual handling education by PCS OT
- A privacy screen
- Developmentally appropriate death and dying discussions for other residents (encouraged to be apart of experience)

What we were able to achieve

- Lucy had a safe and considered death in her own home
- Partnership in action ‘mutual trust and respect’
- Clear role delineation
- Home death was seen as a positive experience for family, carers and organisation
- Carers acknowledged own strengths and new insights
- can now say ‘we are able to provide end of life care here’
- Other residents responses surprising and over whelming
- Improved the health and ‘death literacy’

What’s in progress ?

- A growing body of literature

International and national programs already underway

- Frameworks for collaborative practice models
- Best Practice Guidelines
- Palliative Care for People with Learning Disabilities (PCPLD) Network
- European Association of Palliative Care Taskforce
- NHS – resources

What can we do with this information now ?

- Tell your own stories ‘grow the knowledge pool’
- Palliative care education for the disability sector
- Invite someone from disability
- Develop a portfolio
- Target GP’s
- encourage proactive development of policy around end of life care

For our service

- Consumer and health care provider information for those living with intellectual disability in group homes

Our strength is in our difference and our value is in our shared knowledge and skills

Questions or comments ?

References and resources

Cross, H, Cameron, M, Marsh & Tuffrey-Wijne, I 2012, 'Practical approaches toward improving end of life care for people with intellectual disabilities: Effectiveness and Sustainability, *Journal of Palliative Medicine,* vol. 15, no. 3, pp. 322- 326

Dunkley, S & Sales, R 2014, 'The challenges of providing palliative care for people with intellectual disabilities: a literature review', *International Journal of Palliative Nursing,* vol. 20, no.6, pp. 279 – 284.

Glaetzer, K 2014, 'Palliative care for a vulnerable population', *Australian Nursing and Midwifery Journal*, vol. 21, no. 10, p. 39.

Mansell, J, Beadle-Brown, J & Bigby, C 2013, 'Implementation of active support in Victoria, Australia: an exploratory study, *Journal of Intellectual and Developmental Disabilities* vol. 38 no.1, pp. 48–58

McLaughlin, D, Barr, O, McIlfatrick, S & McConkey, R 2014, 'Developing a best practice model for partnership practice between specialist palliative care and intellectual disability services: A mixed method Study, , *Journal of Palliative Medicine*, vol. 28, no. 10, pp. 1213 – 1221.

Read, S & Cartlidge, D 2012, 'Critical reflection of end of life care for people with intellectual disabilities: a single case study approach, *International Journal of Palliative Nursing,* vol. 18, no. 1, pp. 23 – 27.

Read, S 2012, Palliative care for people with intellectual disabilities: pitfalls and potential, *Palliative Medicine*, vol. 27. no. 1, pp. 3- 4.

Stein, G 2008, 'Providing palliative care to people with intellectual disabilities: services, staff knowledge and challenges', *Journal of Palliative Medicine,* vol. 11, no. 9, pp. 1241-1248.

Tuffrey-Wijne, I 2012, 'Palliative care for people with intellectual disabilities', *International Journal of Palliative Nursing,* vol. 18, no. 6, pp. 264- 266