

End of Life Care Issues

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Palliative Care and End of Life

As illness progresses, harder to ascertain wishes of the person who has dementia especially when the person has a pre existing intellectual disability.

- **Can experience barriers in accessing quality health care for serious illness including Palliative Care.**
- **Importance of preparation for end of life from the time of diagnosis and onwards.**

Holistic approach needed.

- **Address Psychological, physical, social, spiritual and religious needs.**
- **So how do we as services promote safety, comfort, dignity and quality of life?**

Role of Multi disciplinary Team

- **Primary Health Care Teams of GP, District Nursing, Palliative Care Services.**

Together with

- **Learning Disability Teams of :
Speech and Language Therapist, Physiotherapist
Occupational therapist, Nursing
Psychiatrist, Psychologist, Social worker**

Ongoing assessment of :

Pain control, breathing difficulties, respiratory secretions, nutrition, safe eating and drinking, continence, mobility/falls, control of seizures, communication, pressure area care, mental health, positive behaviour support, environmental adaptations, daily living activities, risk management.

Decision making, support for carers.

Last Year of Life

- GPs will be providing the ‘Deciding Right’ personalised care plan for patients with long term life limiting health conditions; patients who are considered to be in their last year of life.
- They will be using the ‘Supportive and Palliative Care Indicators Tool’ (SPICT)

<http://www.spict.org.uk/the-spict/>

Last year of life

- **This will note their care and advanced wishes. Where completed they will be in patients homes in a green folder or a folder with a green tab. There will be a green sticker available to put into the fridge information system. (Leicestershire)**

Last Days

Priorities of Care for the Dying Person – Leadership Alliance June 2014. Replacement for Liverpool Care Pathway.

5 key points:

- **Recognition**
- **Communication**
- **Involvement**
- **Support**
- **Plan and do**

Resources

- Handbook 'Making Choices in End of life Care' LPT
- Palliative Care for People with Learning Disabilities... 'End of life care when I die'
- Disdat
- Communication passport
- Life story work
- A and E Grab Sheet . Hospital booklet...
- Papers on the stand, copies for ref only.

DNR/CPR

- **Capacity assessments/ best interests**
- **Use of DNR**

Introduction

- There is guidance & resources about how to provide care, how can we do it as not straight forward. Many narratives around death and dying that mean people don't get a good death & also fail to think about it
- Need to make more explicit what our assumptions are about death and dying to ensure we are able to provide good care, that this meaningful for the person
- Role of psychologist
- Need to start early (in person's life). Eg PCP -> Life Story, Life Cycle, planning funeral

Context

- There are as many different ways to die as there are different ways to live (Fredman, 1997).
- There are many different beliefs about death (can be contradictory) informed by past relationships, past experiences, families, our own culture, the culture in which we live, our religion, our education, our professions and the law (Pearce, 1994).
- Our personal and professional beliefs might be different (Fredman, 1997).

Questions I've used (Fredman, 1997)

- How do you explain death to yourself?
- Which ideas are you most comfortable with?
- What do you believe happens when people die/after people die?
- What are the stories from your religion, or/and culture?
- If you were a man or woman would you think differently?
- Other views from culture, family, religion, clients or training?

Professional Ideas

- Kubler-Ross (1970) Stages
- Murray Parkes (1972) Phases
- Bowlby (1989) Phases
- Worden (1991) Tasks
- White (1989) Re-membering

Discourses in society (Whitney & Smith, 2010)

- Death has always been an integral part of human existence; therefore, death must be given credence as a pivotal component within individual life trajectories as it is, ultimately (regardless of one's beliefs of afterlife), the end of “biological” life.
- “Death has become medicalized, routinized, and normalized in such a way that it is often devoid of meaning”.

Discourses in society

- Kauffman (1992) refers to this as a cultural conversation in which a “good death” or “death with dignity” is conceptualized in relation to “personal control in dying on the one hand, and on the other hand, the pain, suffering, loneliness, and lack of autonomy brought about by the use of advanced technology medicine in the hospital setting” (p. 715).

Societal ideas

- Different beliefs about talking about death and grieving. Death depresses people
- Good deaths are painfree & peaceful
- There are rights way to die and grieve
- Living and Dying with dignity
- Talking will make it better vs. talking will make it worse
- Death is too frightening to talk openly about 'staring at the sun'
- You have to have done or achieved everything you want and have had a good life before you die
- You have to have 'made peace' in all your relationships when you are dying
- You have to feel 100% positively towards people who are dying, 'you can't talk ill about the dead'

Ideas about acceptance (Fredman, 1997)

- Idea of accepting death and dying. The opposite is called denial. There is concern that someone will get stuck in grieving if they do not accept death
- Acceptance is rational whereas hopes for ensuing death might be seen as denial and not good for mental health
- Dying is not always a beautiful affair, and how people die can live in the memories of those who live on
- Others can't manage grief so a referral is made to a specialist
- Advice about talking from professionals (important for a 'good death' vs death talk as taboo)

Context of Learning Disability

- “Sometimes, I use ideas to help me and sometimes they don’t help, and I get overwhelmed with unnameable feelings. There are the territories where words prove their limitations and poets may be required (Campbell, 2009).
- Added complexity within the population of PWLD when concept of death may not be clear (McEvoy, MacHale & Tierney, 2012). Language may be a challenge (examples).

Assessment of Concepts of Death

Concept of Death

	Concept	Question	Response
1	Causality	What makes people die? (illness, disease, biological, wearing out)	
2	Irrevocability	Can you make dead people come back to life?	
3	Universality	Do things die? Does everybody die? Do you think you will die?	

Dr Judith Samuel

Assessment of Concepts of Death 2

4	Dysfunctional	When someone dies can they still move, breath, hear, see?	
5	Appearance	What happens next? (to a dead persons body)	
6	Afterlife	What happens to a person after they are dead? (<u>afterlife?</u>)	

Dr Judith Samuel

Ideas around PWLD

- Context of knowing and telling
- People need to be learning, developing, increasing independence
- Fear about how others clients will cope, or that they won't notice their friend is changing
- They won't understand anyway
- Professionals shouldn't be sad in front of their client or even about them (professional veneer)

Some examples of my own beliefs

- **My psychology training:** I should help bereaved people to grieve appropriately. Complex grief is different from grief.
- **My systemic training:** There is no right way to mourn; listen to feedback. What values are important to the client.
- **My experience with staff teams:** Grief & death talk needs professional expertise.
- **My team:** Grief is normal we only work with complex grief.
- **My culture:**
- **My experience with PWLD:**
- **My personal experience:**

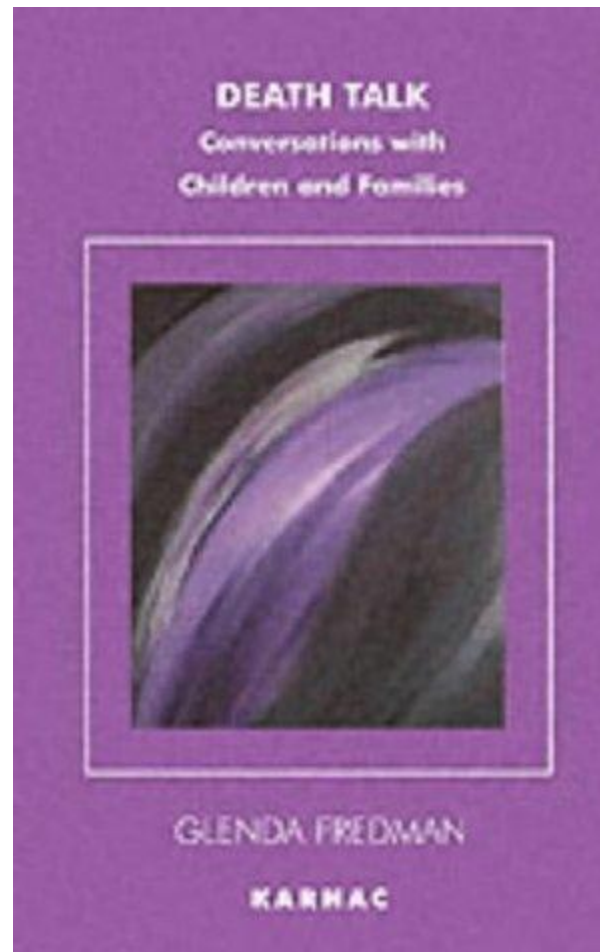
Task Part 1

- Keeping ourselves safe – health warning
- In groups of 3 talk about ideas about death and dying from society, your family, religion, clients and training.
- Which stories do you draw on from each context and which stories or ideas do you prefer?
- Are they similar or different? Are any very different? What happens when your stories fit together well or contradict each other?

Task Part 2

- Within the system around a person with LD and dementia, what stories might there be? Would they pose challenges to providing them with good care?
- How would you negotiate these challenges?

Recommended Reading



Recommended Reading

