How to engage loved ones in the death process to minimise regret and complicated grief

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Warning this talk contains graphic and potentially distressing photos and details

Basic Question

- When you love someone where do you want to be?

The History of Death

Realities of Death

- All deaths – sudden or expected are sad.
- They do not however all need to be disempowering and traumatic
- The importance of time, respect, personality, culture, spirituality and love can not be forgotten.

Good Death Work

- Respect
- Creativity
- Flexibility
- Advocacy
- Constant Learning

Scenario

- Palliative or Acute
- People want to make things ‘better’
- This can happen

Core Assessment

1. Language
2. Who/where is the family?
3. Is everyone safe?
4. Have they ever been in a ED/ICU/hospital before?
5. What do they understand is happening?
6. Significant loss and crisis history
7. Mental and physical health history

Core Assessment

1. Concurrent Stressors
2. Concerns of responsibility, guilt or blame (do not want these to become central beliefs or personal narrative)
3. Protective and Risk Factors
4. Cultural and Religious Beliefs

Communication

Family Presence during resuscitation

- Offer family members the opportunity to be present during resuscitation whenever possible.
- No cases of litigation or negative effects from families in the research
- Essential to have a person with no patient care responsibilities to stay with the family and assess, monitor and inform

(Curley et al, 2012, Knapp, 2005; O'Connell 2007; Dingeman, et al 2007, Farah et al, 2007)

Interventions During Resuscitation

- Explain process to family
- Small words of comfort and knowledge
- Provide security, leadership, stability and consistency
- Walk them through this process

- Ensure understanding
- Facilitate communication and family meetings
- Be gentle but honest
- Role with extended family
- Can be physically demanding

Families need Communication

- Accessible
- Honest
- Pace they can absorb
- Language they can understand
- Don't be afraid by silence and emotion
- To be heard
- Empathy and compassion
- Perception they made good medical decisions

(Midson et al , 2010; Meert et al, 2008; Hinds et al 2009)

What families value…

- Deep sadness but no regrets
- "To do the right thing"
- To be an advocate
- Opportunity to convey love and be present
- Not allow suffering
- Personal connection with staff
- Need for truth, trust and compassion

(HINDS et al, 2009)

What does 'Dead' look like?

- Anything

After Death

- ONLY RESPONSIBILITY IS TO RESPECT THE PERSON'S BODY & MINIMISE FAMILY REGRET
- No rush
- Give the person back to family.

What can be done to help?

- Respond to the emotional, cultural, procedural, and legal issues.
- Even brief interactions with family's can have a profound and enduring impact.
- People impacted by death are diverse
- No single policy, plan, or approach can address all the situations and circumstances of death.

(Knapp et al, 2005)

What does ‘normal’ grief look like?

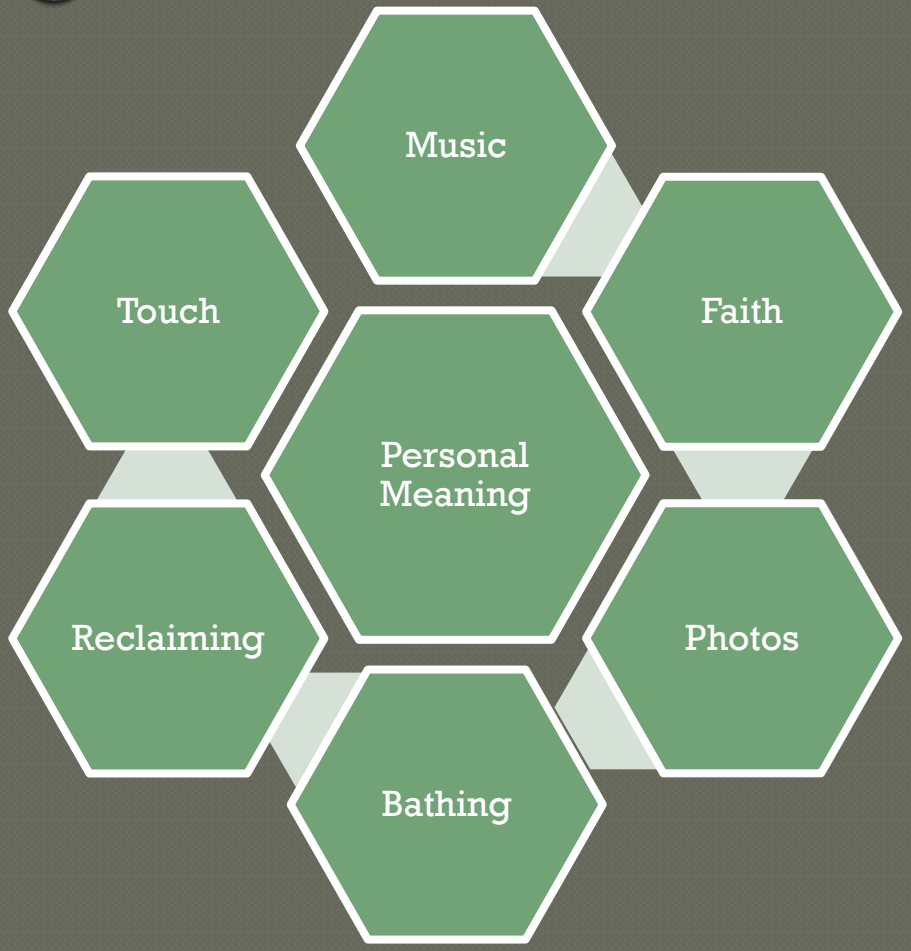
Spiritual Needs

- Spirituality and religion are complex, multidimensional phenomena with distinct and overlapping domains
- Prayer and sacred texts;
- ritual,
- connection with others;
- meaning and purpose;

(Meert, et al 2005)

- Chance to explore where their loved one may ‘go’

Building Memories in Death

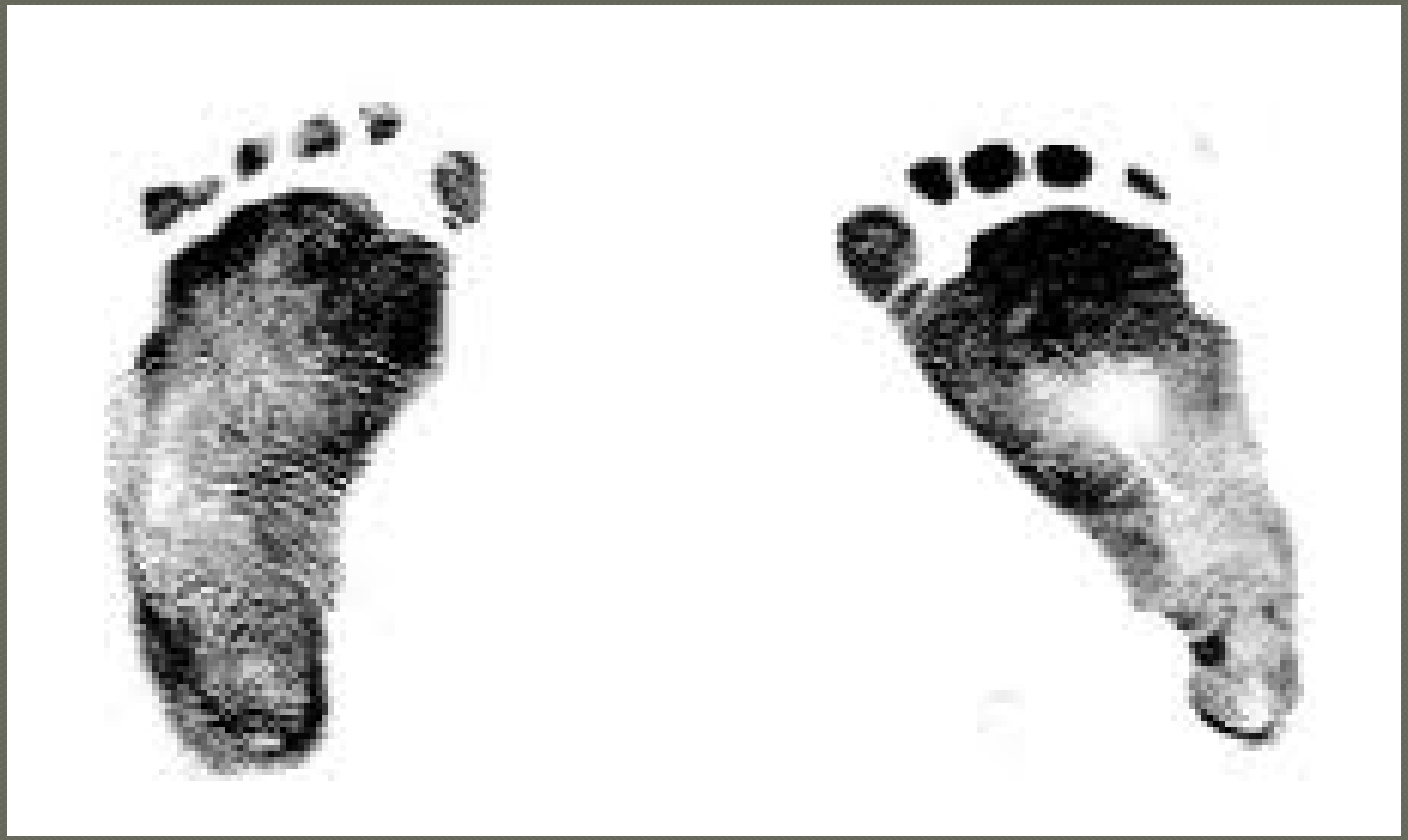


Memory Making

- For some siblings memory making will be the only activity they ever do with their baby brother or sister
- Rub in creams
- Assist with baths
- Joint hand and foot prints
- Video activities
- Take photos

PHOTOS & TOUCH

Hand and Foot Prints




KIA PRIDMORE
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Acute Critical Stress Symptoms

- subjective sense of numbing, detachment, or absence of emotional responsiveness
- a reduction in awareness of surroundings
  - derealisation - sense that world is unreal, strange, unfamiliar.
  - significant distress or impairment in social, occupational, functioning
  - impairs the individual's ability to pursue tasks, or mobilizing personal resources by telling family members about the traumatic experience.

(CISM Website)

Tissue and Organ Donation

- Brain Death– two tests done by two different consultants. Irreversible cessation of all function of the brain requires certification by two (2) medical practitioners each of whom has carried out a clinical examination of the person
- Donation after Cardiac Death – following 5 minutes of continued absence of circulation demonstrating irreversibility evidenced by absent palpable central pulse and a pulse pressure of zero
- Donate Life consultants will do the majority of talking however do sit in and offer support Important to know that it can delay death for 12-24 hours sometimes longer.

Autopsy and Genetics

- Provide important questions in the future
- Can be very important for genetics and future children or relatives
- Provide a correlation of clinical diagnosis and clinical symptoms
- Determine the effects of therapy
- Study the natural course of disease processes
- Educate students, physicians and others

Issues at time of death

- "I am never going to leave my loved one"
- Fear of removing tubes and medical equipment
- Police presenting before the family are ready to leave
- Guarding the family's privacy from staff, media, other family
- Sedation
- Length of stay with body

Post Bereavement

- Family meeting with Consultant and SW 6-8 weeks after death
- Aims:
  - Go through 'what happened'
  - Assure family that everything was done
  - Assure family that they did well
  - Mentor and assist Drs with communication
- Ask clarifying questions on behalf of the family

(Eggly, et al 2011)

Bereavement Follow Up

- Small take up on extensive bereavement counselling
- We do not give information at time of death
- Phone call in the days following death 6 weeks – offer family meeting
- Post mortem/Coronial feedback
- First birthday
- First anniversary
- First Christmas

Summary

- All deaths are sad
- Death can also be intimate, beautiful and meaningful
- Remain flexible and creative at all times
- Learn constantly
- Be prepared for anything
- Care for self.