


Principles of Children's
Palliative Care /
End of Life Care Planning
& Collaborative Practice



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Spirituality at End of Life

Thomas Begley
Chaplain, LauraLynn




This presentation will focus:

- Conversations; Scenarios and Characteristics of Spirituality at EOL
- Culture Faith or Non-Practice: How these play a part
- Rituals/ Death Rituals



Some questions to think about:

- What does spirituality look like for you in your life ?
- Have you used it in supporting children at EOL and their families ?
- Where do you receive your spiritual support from?




Role of All / Chaplain at EOL

- How spiritual care is offered
- Being available & present to Child & Family
- Drawing on my own faith / spirituality
- Having a compassionate heart
- Attentively Present: Listening *"with ears of the heart"*
- Forming a trusting relationship
- Respecting those who do not wish to engage spiritually
- Meeting all family members / significant others:
- Discern where they are at re: spiritually faith or none or otherwise




Conversations in Spirituality EOL

- Pray for each family member by name
- Find out what they want / ask them again
Check in with them later on
- How can I help you: How can I support you ?
- Find out concerns worries issues questions
Discern.... Let God
- Difficult conversations with family / with another member of the Team



Some true conversations & scenarios encountered @ EOL

- Fear around death: Death of their child
- Parents on "different pages", Fear in losing their identity
- Estranged, challenging, parents, families
- Innocent suffering of child: the unfairness injustice: the anger this generates
- Why does God allow this to happen ?
- Funeral undertakers
- Engaging with siblings



The Ultimate Sacred Space

- The dying hours moments of a sick child is a truly profound sacred private family space
- A precious dignified time “A one off”
- A never to be forgotten Ending
- In my view where the divine breathes on humanity
- One of life’s Solemn Moment’s for a family
- Let’s respect this time and Sacred Space



Conversations in Spirituality

- “How can I support you spiritually” ?
- Be cognisant with children / families different spiritually / faith or none: Have the conversation with them!
- Some families may be at different levels in their faith beliefs..... A la carte, Pick and mix
- If appropriate and without intrusion
- Spiritual needs support, Music, Photography Play, Memory & Legacy Making



Spiritual care at EOL

- Spiritual Care at EOL is like an umbrella Covering over ...palliates... the hidden inner spiritual life: Comforting often the inarticulate unspoken needs and desires. Often going beyond what we are seeing hearing observing..... Sitting quietly with a family & their pain... learning to be comfortable in a truly agonising harrowing situation... Holding this Grace assisted experience.



Culture Spiritual Care at EOL

- A Family’s culture: How we do things religiously spiritually
- Awareness of our own faith spiritual cultural practises at EOL
- Awareness of others different from ourselves. See HSE Inter cultural guide
- Taking a lead from families irrespective of differences to ourselves
- Awareness some children / families are not fully practising faith within their own culture



- Think about our Faith, Spirituality, Culture. We may have difficulties in articulating these for ourselves in normal circumstances.
- Think about families who are different spiritually, culturally, religiously, ethnically: English-2nd language
- How well do we Communicate to them?
- How well do we facilitate them to communicate respond interact understand interpret information under duress ?



An Islamic Perspective

- A family whose child is @EOL rely on their own resources such as faith : networks: their view of & resilience to suffering & their previous experience of death & loss may determine how they will cope
- An Islamic Perspective: “On no soul does Allah place a burden greater than it can bear” Quran 2:286 : “One is to adopt Sabr [patience] in the face of distress
- Distress faced by a believer will raise their spiritual resolve & character.



Can you name some rituals related to death and dying?



Rituals

- Every society practises rituals
- Family, Domestic, Local, Civil, Religious, Military, State
- Dress code: Gathering: Procession: "Giving Away" Music: Readings : Candles lit : Rings: Vows Spoken : Celebration Party
- Civil or Religious for most Cultures



Rituals

- Death rituals [funerals] for children: Why have them ?
- One of the last acts of love a parent can give to their deceased Child
- It is a human, social, religious, civil & custom
- It is a public acknowledgment, celebration, Remembering, Honouring of a Childs Life Acknowledgment of the family's grief.
(N.Ball BCH 2011)



- The Death Ritual for a child's [funeral] is a space and opportunity to express sorrow with affirmation
- The Rituals spiritually bring grace & blessings to the deceased
- Can bring solace and hope to the bereaved Can be an antidote to spiritual pain
- Acknowledgement Child is at peace : pain free sharing a New Life now with God [Christian Islam]



- Ritual for Deceased Children
- Meaningful : Well structured : Child friendly Prepared: Simple : Reverent : Fluid : Time yet not rushed:
- Inter generational participation
- Formal & Informal parts to it
- Pitch & Pace Ambience that enhances ritual
- God is present



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- **Thank you for Listening**
- **Thomas Begley, Chaplain**

