Accompanying the dying child and family to the end-of-life

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“Seasons” in the family’s trajectory through the child’s illness

1. Season of **Violent Disruptions** associated with the diagnosis
2. Season of **Striving for Normalcy** often in the midst of transitions
3. Season of **Liminality**
4. Season of **Separation**
Season of Liminality

"limen" in Latin = threshold
Living between two worlds

- Child is **neither well enough** to lead a ‘normal’ life, nor dying

The mermaid queen

*Sophia,*
15 years old
Ambiguous Loss

- Ambiguous is a loss that remains unclear

- The child is physically present BUT psychologically absent due to major changes in physical condition, psychosocial well-being & ways of relating to others.

- Family members feel they have “lost” the child, who is still alive.
Advance Care Planning

- Define and redefine goals of care
- Consider alternative options, potential scenarios, without engaging in definitive plans. Keep all options open!
  

- Address communication issues with seriously ill children and siblings
  - How to address “difficult” topics
  - What to disclose
  - How to share information
  - When to engage in discussions

  Aldridge et al., 2017 – “I can’t tell my child they are dying; Helping parents have conversations with their child. *Arch Dis Child Educ Pract Ed* (on line)
The circle of my feelings

Red: Loneliness
Blue: Fear
Green: Anger
Black: Sadness
Pink: Joy
Grey: Guilt
Maria,
7 year old

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siblings in the shadow….  
(when the ‘world of illness’ intrudes into ‘ordinary life’)  

- have several **unanswered questions**  
- **fear** they may get sick too  
- are **jealous** of the attention that the ill child receives, and feel guilty about it  
- are **deprived of opportunities** that peers have  
- manifest **physical & psychosocial difficulties**  
  (e.g. sleep problems, school problems with other children or school-work, physical complaints).
Season of Separation
Immersion into the “World of Illness”

**Anticipatory grief:** A process involving an active adaptation to the reality of impending death manifested through….

- Worries about deterioration & prospect of death
- Separation anxiety
- Emotional withdrawal (except from few relations)
- Concerns about location of care and death
- Direct or indirect communication of farewells

“My victory”  Lito, 14 years old
Both are transitional periods

Both evoke losses and a grieving process

Both involve a process of definition of self (Who Am I?) and one’s belonging in life (What is my place in Life?)

Both trigger an active search for meaning

Both involve major inner psychic reorganizations
Who am I? (present)

Who was I? (past)

Who would I like become …… but will never be? (imagined future)

Where am I going after death? (immediate future)

How I wish to be remembered (long-term future, immortality)


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A life “worth living”
is a life filled with...

ordinary activities
and
ordinary relationships
with siblings, parents, relatives, peers, boyfriends or girlfriends etc,

which are experienced as extra-ordinary
and lived with an acute vitality that offers a renewed sense of existence in the world.

“Companion”

Latin root

Com = with + Pan = bread

Companion is someone who breaks bread with a person, while listening to stories
Accompanying children & families

Create a **SAFE HAVEN**
that responds to needs for safety, order, predictability in times of adversity

Provide a **SECURE BASE**
that facilitates explorative behaviors in unfamiliar situations

Ability for **HOLDING**
& containing suffering
(by “bracketing” our subjectivity)

Ability to facilitate **EXPLORATION**
of unfamiliar situations
(by empowering, guiding, encouraging)

Elli,
7 years old

“The wild Jungle”

“The house is called Danai”

“With a lot of love, your friend, Elli
To my beloved Danai”
‘Rippling’ refers to the fact that each of us creates -often without our conscious intent or knowledge- concentric circles of influence that may affect others for years, even for generations.”

Irvin Yalom