

Demystifying the Difficult

Sharon Reynolds CNS
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“ I’m not dying.... I don’t need to see palliative care..”

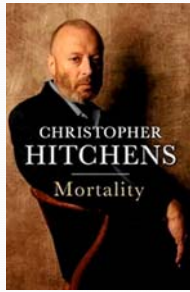
“ It freaked us out when you came in the room.... No one has called palliative care before. Why now?”



Not today....

“ I don’t want you speaking to my husband. If he hears the word palliative care he will think death is near..”

“.....don’t take my hope away..”



"The absorbing fact about being mortally sick is that you spend a good deal of time Preparing yourself to die with some modicum of stoicism..... While being simultaneously highly interested in the business of survival....one has to exist even more than usual in a **DOUBLE FRAME OF MIND**" P.7

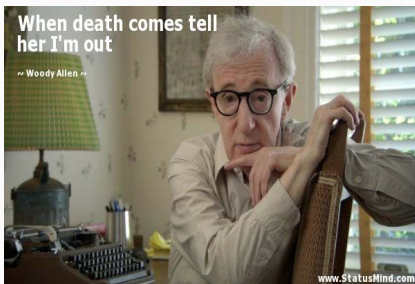
Grief is....

"A psychosis, is implosive, explosive, arbitrary, unjust....."

Sandra Bertman
Grief and the Healing Arts (1999)



The logo for 'Just Ask!' features the words 'Just Ask!' in a bold, white, sans-serif font. The text is contained within a green square that is slightly offset to the right, creating a 3D effect.



A STORY ABOUT ROSITA

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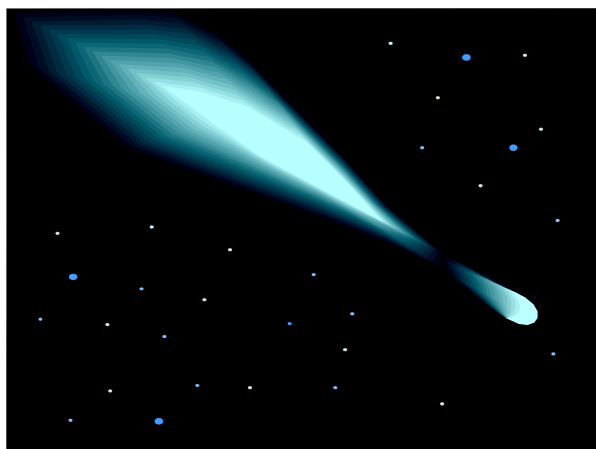
"Watching a peaceful death of a human being reminds us of a falling star; one of a million lights in a vast sky that flares up for a brief moment only to disappear into the endless night forever."

Elizabeth Kubler-Ross



A model for communication

- ▣ Balfour Mount (2005):
 - Recognizing the uniqueness of each individual
 - The shared vulnerability of the human condition
- ▣ Shifting from an impersonal ("I-it relating") toward a more shared/openness ("I-thou relating") (Martin Buber)
- ▣ "emotional labour" in caring for another



Meeting Rosita

- ▣ Illness Presentation:
 - 44 y.o. female, admitted at the recommendation of her Family M.D. after an abnormal CXR
 - Diagnosed with metastatic breast cancer to lungs, bones, brain (frontal lobe)
 - Prior to hospital admission, had been followed by Mental Health for depression/anxiety/unusual behaviour
 - Seen by Medical Oncology (PMH) and was put on oral chemo (hormonal)

▣ Goals of Care:

- Full Code
- She understood her advanced cancer diagnosis and the uncertainty of her future
- Her main focus was on: *"getting better"* in order to be there for her kids

▣ Social History:

- Originally from South America
- Mother to a 12 year girl and a 8 year old boy
- Separated from her children's father but were in regular contact
- Recently separated from her boyfriend
- Children primarily lived with their father
- Her mother and best friend were her primary support system

▣ Hospital Course:

- Bed bound throughout her stay
- Extremely cachexic
- Abnormal behaviour...constant picking away the edges of her nose
- Regular visits by Mental Health and our palliative team
- Disease progressed in her pharynx and received a short course of palliative radiation to reduce/stop bleeding

▣ Rosita's Final Day:

- She could no longer speak
- Had great difficulty using her "communication board"
- Now needed Oxygen by Face Mask
- Medical Team spoke with family about DNR – but family felt that Rosita needed to be part of discussion
- Medical Team were unsuccessful in obtaining a "DNR Order" from Rosita



My concerns...

- She was dying...did she know this?
- She was still a full code
- I wanted her to die with dignity...
- ...and given an opportunity to prepare herself and her family for her death
- How about the kids? Did they know about Mom's illness?

☐ Use of my 'therapeutic self'

- Being with another in their utter suffering, emotional pain, in their grieving

☐ Presence with another

- 2011 study (Bailey et al) showed that good care at EOL was associated with "presence" and nurses "being with" patients
- Poor experiences of care (for both patients/families) resulted from a "lack of a close nurse-patient relationship"

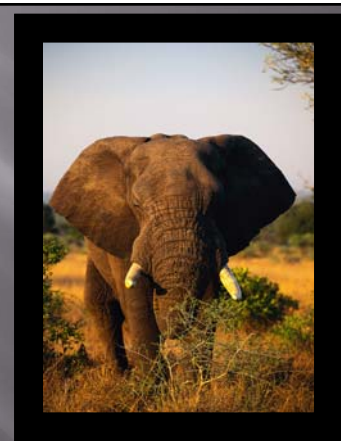


"When the conspiracy of silence is broken and loved ones talk openly about the death that is approaching them, then their fears, needs and hopes are met more readily and the path cleared for coming to grips with the reality they face."

Unknown

A need to address the Elephant in the Room!

The fear of death ...
...and fear of dying



Guiding Rosita as she transitioned toward an EOL focus

- ☐ Being present with her in her suffering
- ☐ Gently reviewing her illness course and the present situation...DNR in the context of the illness
- ☐ Supporting her in her grief...
- ☐ ... "Oh no, I don't want to die"
- ☐ Supporting her family
- ☐ Preparing the children for death



Pearls in guiding others at EOL

- ▣ Be yourself...know your limits and your strengths
- ▣ Allow yourself to be challenged
- ▣ Acknowledge that "death" is the larger reality behind patient's acceptance of a palliative care focus
- ▣ Be mindful of how you communicate

"The nearer the patient approaches death,
the more he reaches out toward life.

Touch is often important, sitting close to him,
holding his hand, staying near him even without
words.

All of these things make the chasm between the
living and the dead less terrifying and lonely."

Hackett & Weisman, 1962