Life After a Serious Diagnosis: What Now?
Understanding Our Role as Spiritual Companions

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• The Clock Ticks
Life After a Serious Diagnosis: What Now?

Topics:

Getting the News
  Person
  Family and Loved Ones
Anticipatory Grief
Coping
  Balancing Hope and Acceptance
Our Role

Getting the News
  – Person
  – Family and Loved Ones
    • (ex: the mother and the vent)
  • PREPARE
  • Three Stories
    – Drowned Child
    – Woman with Pancreatic Cancer
    – Mad Dog
Giving and Getting the News - Patient

- THE DOCTOR

http://www.youtube.com/watch?v=OIPv-pjABbk

- Delivering a Cancer Diagnosis 50/50

http://www.videojug.com/interview/receiving-a-cancer-diagnosis-4

PREPARE
- P - Prepare for the Discussion (Multidisciplinary Team)
- R - Relate to the Person
- E - Elicit Patient and Caregivers Preferences
  - Elicit Expectations, clarify understanding, aware of cultural religious conditions.
- P - Provide Information
- A - Acknowledge Emotions and Concerns
- R - Realistic Hope is Fostered
- E - Encourage Questions and Discussions
- D - Document the Discussion

  – mndcare -clayton and others 2007
Getting the News

• Shell Shock
• Three Stories
  – Woman with Pancreatic Cancer
  – Drowned Child
  – Mad Dog

Anticipatory Grief

Definition - The name given to the angst and sorrow that accompanies the knowledge that one is going to die. One fears the loss that is coming more than actually grieving it.

(Greg Harvey - Dealing with Anticipatory Grief and Caregiving - For Dummies - 2012)
Anticipatory Grief - (Harvey)

“Many people mistakenly believe that, in suffering anticipatory grief, they lessen the grief that they’ll experience when death finally comes. Unfortunately that is not so.”

“Don't ignore the feelings of angst and stress associated with anticipatory grief and with caregiving for a loved one. Instead, **find ways to express and validate your feelings**. Seek the help of family or grief counselors, social workers, or psychologists in order to keep yourself going. If you're a primary caregiver, you also may need to get some help with the care giving from other family members, community services, or a hospice team. Although you may feel as though you have to "keep it together“ in order to be an effective caregiver, you may actually be less effective if you don't deal with the psychological tolls from the stresses related to care giving.”

e.g. - D word

Anticipatory Grief - (Harvey)

Signs -

Sorrow and Rage,
Bouts of Depression,
Feelings of Being Drained

Caregivers

Burnout
Isolation
Resentment toward Loved One
Guilt
Helplessness
Anticipatory Grief - (from anticipatory grief blog)

The Gradual Reality of Impending Loss,

• Phase I -
  – Patient - Sadness and Depression
  – Family - Realization that Death is Inevitable

• Phase II -
  – Patient - Withdrawn, Closed (need closeness) Sense of Injustice, Helplessness
  – Family - Concern to Reconcile Differences, want to help with “Fear of Death”

• Phase III -
  – Patient - Request Wants and Expectations
  – Family - Stay Close, arrange Good Byes

• Phase IV -
  – Patient - Person worsens, may discuss death
  – Family - Begin imagining what life will be like without the person.
Coping - Balancing Hope and Acceptance

Hope for Cure

Acceptance of Death

It goes back and forth

Do we fight our disease, or accept them as a part of our journey?

Making Peace with the Disease?

Our Role

• Awareness of Signs
  – Five Stages
  – Psychological
  – Physiological
  – Emotional
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Our Role

• Awareness of Signs - (Kutscher Phenomenon of Death 1973)
  – Five Stages of Grief (Kubla-Ross)
    • Denial
    • Anger
    • Bargaining
    • Depression
    • Acceptance

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Our Role

• Awareness of Signs - Psychological
  – Disbelief of Medical Evidence
  – Isolation of Self
  – Fear Sharing of Thoughts
  – Brutal Responses
  – Anger toward God
  – Anger toward Self
  – Worry about Loved ones
  – Bargain with God - Hard Prayer
Our Role

- Awareness of Signs - Physiological
  - Neglect of Self
  - Prone to other Diseases
  - Aches not Related to Illnesses

Our Role

- Awareness of Signs - Emotional
  - Distrust
  - Silent
  - Obsessive about all things
  - Refusal
  - Anxiousness
  - Fear of Dying and Dying Process
• Our Role
  – Listen - unique ability to be present
  – Acceptance - No one has to progress according to any time table
  – Love - Patient and Family
  – Comfort - Be there
  – Compassion - Heart and Head