END OF LIFE CARE: THE CARES MODEL

Bonnie Freeman  DNP, ANP, ACHPN
Supportive Care Medicine

How the Experts Treat Hematologic Malignancies
Las Vegas, NV
March 11, 2016
Disclosure Statement

The presenter of this lecture does not have any relationship with industry or any commercial interests that might affect the presentation, and therefore has nothing to disclose.
Objectives

- Introduce and promote understanding of how to utilize the CARES Tool.
- Promote the importance of acting as a patient advocate for the dying and their family.
- Increase understanding of the concepts of hope.
- Encourage communication and promote its importance when caring for the dying and their family.
- Provide methods to consider for development of personal self-care.
Symptom Management Needs of the Dying (Freeman, 2015)

Diagram showing the symptom management needs of the dying, with pain and dyspnea being the most significant symptoms, followed by delirium and N/V.
Common Needs of the Dying

Based on 68 Studies

- Symptoms 41%
- Spiritual 37%
- Self Care 22%

(Freeman, 2015)
The CARES Tool Organization and Considerations

The CARES tool is an acronym organized educational tool that addresses the most common symptom management needs of the dying:

- **C**omfort
- **A**irway
- **R**estlessness and delirium
- **E**motional and spiritual support
- **S**elf-care.

(Freeman, 2013)
Comfort

• Act as a patient advocate.
• 90% of patients die in pain
• If they were in pain before they became unresponsive, they are probably still in pain.
• There will always be a last dose.
• Intent.
• More likely to die of their disease than from the opioids.
• There is no maximum dose of opioids for pain control.

(Byock, 2012; LeGrand & Walsh, 2011; & Quill, 1998)
The Focus of Care is Comfort

Evaluate need for procedures, tests and activities. Provide as much time for the patient and family to be together as possible. (Ferrell & Coyle, 2010)

- Stop or modify vital signs.
- Stop nonessential medications.
- Clarify IV fluids.
- Stop or reduce tube feedings.
- Turn off monitors and alarms.
- Stop or decrease labs.
- Discontinue isolation. (Freeman, 2015)
Comfort

- **Never underestimate the power of a washcloth.**
- Be a Patient and Family Advocate.
- Explain the difference between a normal dying process and suffering.  
  (Ferrell & Coyle, 2010)
Airway

- Shortness of breath can be reduced with use of a fan.
- Explain agonal breathing vs. suffering.
- Use of supplemental oxygen is more for the family.
- Control death rattle.
- Morphine is still the gold standard of care.
- Emphasize use of touch and talking to patient.

(Ferrell & Coyle, 2010)
Restlessness and Delirium

- Rule out treatable causes.
- Address possible unfinished business.
- Importance of saying good-bye and to give permission to stop fighting.
- Important family event or anniversary.

Educate the family:
- Patient lacks awareness of behavior
- Possible to be peacefully confused.

(Ferrell & Coyle, 2010)
Restlessness and Delirium

(Freeman, 2015)

Let Grandma Stay in the Bahamas
Emotional and Spiritual

• Caring for the soul.
• Know your resources.
• Focus on retaining the patient’s dignity and feelings of value.
• Every family is unique and grieves differently.

(Pulchalski & Ferrell, 2012)

Good Communication is Essential.
The ELEPHANT in the Room
Emotional and Spiritual Support

**Just be** with patient and family.
Work with family to provide favorite activities, smells, sounds, etc.
Support rituals.

**Your humanity is needed the most.**

**Always be available.**
The **family** becomes your focus.
- Be sure families are getting rest and breaks.
- Provide coffee, water, etc.
- Continue to be available to answer questions.

(Ferrell & Coyle, 2010)
Emotional and Spiritual

(Freeman, 2015)

Celebrate the Person.
They are NOT their disease.
Promoting Hope

• No universal meaning of hope.
• Hope is generated from within and supported by others.
• Reality is a prerequisite for hope.
• Realistic or authentic hope is thought to have the potential to change human existence for the better without reaching for the unattainable.
• Concern over loss of hope by healthcare providers actually prevents its evolution.

(Longaker, 2001 & Macleod, 2011)
Promoting Hope

- Hope is not just focused on a cure
- Hope must he allowed to grow and evolve
  - Hope to live a long life
  - Hope to be able to enjoy life
  - Hope that pain will be controlled
  - Hope that my family will be okay
  - Hope that I made a difference
  - Hope that I won’t be a burden
  - Hope that I won’t die alone
  - Hope that my death will be peaceful

(Duggleby, 2001; Ersek, 2006 & Groopman, 2004)
Hope Must Be Fueled
An Individual Must Feel:

• They are more than their disease
• They are valued
• They can still contribute
• They are respected
• They are loved
• They are honored
• They will be missed
• They are still a unique human being deserving of compassion

(Duggleby, 2001; Groopman, 2004; & Thurston, Wilson, Hewitt, 2011)
Self-Care

- **Allow yourself to be human.**
- **Professional grieving**
  - It’s okay to cry.
- **Importance of debriefing**
  - Tea for the Soul
  - Hope Rounds
- **Challenges and privilege of assisting a fellow human being through the dying process.** (Ferrell & Coyle, 2010)
- **Acknowledging the spiritual impact of witnessing death.** (Freeman, 2015)
Self-Care Issues

- Moral distress
- Death anxiety
- Soul Injury
- Exploring how your care made a difference.
- Reviewing effective communication techniques, available resources and support.

(Lang, Thom, & Kline, 2008)
Self-Care Pearls

- Do not believe the pedestal you were placed upon.
- A power greater than you will decide your patient’s fate.
- DO NOT EQUATE DEATH WITH FAILURE.
- Take comfort in knowing you did your very best.
- Learn to celebrate the journey.
- Review your day and give yourself quiet time.
  - Recognize parallels that lead to over-identification.
  - Identify unresolved grief.
  - Challenge yourself to understand why the event/situation was so upsetting.
- Stay in the present.
- Eat healthy, get your rest, and try to exercise.
- Find laughter and joy and make it a daily part of your life.
- Identify some meaning or growth from the experience.
- Learn to “Ride the Dragon”.
- Do not fear professional grieving for it is when the heart is most broken that we are the most open to change and personal growth.

www.carestool.com
CARES Tool

- Intended to supplement end-of-life care education.
- Provides suggestions and prompts on individualized patient and family-driven evidence-based care of the dying.
- Identifying common teaching and communication needs.
- Encouraging holistic support during the last few days to hours of a patient’s life.

(Freeman, 2015)
• Staffing assignments must change.
• Caring for an actively dying patient must be given priority.
• Nurses must value just being present, listening, and providing care for both the patient and family.
• They may not remember what you did, but they will remember how you made them feel.

**WE MUST BECOME THE VOICE OF THE DYING.**

(Freeman, 2015)
• Be pro-active and anticipate.
• Request a Palliative Care consult.
• Celebrate the person— they are not their disease.
• Nurses cannot change the fact their patient will die but they have everything to say about the journey.

“Its all about the journey.”

(Freeman, 2015)
“It is the power of our own humanity that can make the difference in the lives of others. We must value this as highly as our own expertise”

(Puchalski & Ferrell, 2010).
“…there are worse things than having someone you love die. Most basic, it is having the person you love die badly, suffering as he or she dies. Worse still is realizing later on that much of his or her suffering was unnecessary.”

(Ira Byock, 2012)
ELNEC

The End-of-Life Nursing Education Consortium (ELNEC) Project is a national end-of-life educational program administered by City of Hope (COH) and the American Association of Colleges of Nursing (AACN) designed to enhance palliative care in nursing. The ELNEC Project was originally funded by a grant from The Robert Wood Johnson Foundation with additional support from funding organizations (Aetna Foundation, Archstone Foundation, California HealthCare Foundation, Cambia Health Foundation, Milbank Foundation for Rehabilitation, National Cancer Institute, Oncology Nursing Foundation, Open Society Institute/Foundation, and the US Department of Veterans Affairs). Further information about the ELNEC Project can be found at: www.aacn.nche.edu/ELNEC.
CITY OF HOPE PAIN & PALLIATIVE CARE RESOURCE CENTER (COHPPRC)

The COHPPRC, a clearinghouse to disseminate information and resources that will enable other individuals and institutions to improve the quality of pain management and palliative care. The COHPPRC, established in 1995, is a central source for collecting a variety of materials including pain assessment tools, patient education materials, quality assurance materials, research instruments and other resources.

Website: http://prc.coh.org


The Beginning