

COMPASSIONATE PERSON-CENTERED CARE OF THE DYING

PART I: INTRODUCTION

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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.

CONFLICT STATEMENT



- ▶ Identify most common symptom management needs of the dying.
- ▶ Increase understanding of the importance of acting as a patient advocate for a dying patient and their family.
- ▶ Improve understanding of pain management issues when caring for the dying.
- ▶ Improve ability to educate family on difference between suffering and a normal process of dying.
- ▶ Increase understanding of the importance of communication.
- ▶ Provide methods to consider for development of personal self-care routine.

OBJECTIVES



PART I: IMPORTANT CONCEPTS

- ▶ Overview of Dying in America
- ▶ Need for Patient Advocacy
- ▶ Basic Physiology of the Dying Body
- ▶ Pain Management for the Dying
- ▶ Communication
- ▶ Emphasis on Self-Care

PART II: THE CARES TOOL

- ▶ Basis of the CARES Tool
- ▶ Comfort
- ▶ Airway
- ▶ Restlessness and Delirium
- ▶ Emotional and Spiritual Distress
- ▶ Self-Care

PART III: GROUP DISCUSSION

Group Work

Discussion

WORK SHOP BREAK DOWN





PART I: IMPORTANT CONCEPTS

- Many of the dying do not fear death as much as they fear how they will die. (Byock, 2012)
- Average initiation of comfort care plans occurs 9 days prior to death.
- 1/3 of the dying continue to receive life sustaining treatment.
- Average prognosis of dying is made 3.8 days prior to death.
- 50% of terminally ill individuals die in pain.
- 80% of the dying will experience sub-optimally treated dyspnea and terminal restlessness or delirium before they die.

(LeGrand & Walsh, 2011; Ong, Yee, & Lee, 2012)

- By 2050, 88.5 million adults in the United States will reach age 65+ years accounting for 20.2% of the population. (Thurston, Wilson, & Hewitt, 2011).
- 85% of all deaths in the United States occur within this 65+ age group. (AMA, 2012; Whitbourne & Whitbourne, 2011)
- 60% of this group will die in a hospital, and 80% to 90% of their deaths will be expected. (Thurston, Wilson, & Hewitt, 2011).
- The average amount of time expended on end-of-life care education in medical and nursing programs is 15 hours. (Dickenson, 2007)

- ▶ Death viewed as a failure.
- ▶ Not discussed, seeing Death Cafes becoming popular
- ▶ Poor response to obtaining advance directives.
- ▶ 1900s Americans died at home from short term illness cared for by family.
- ▶ Changed with WWI and discovery of antibiotics.
- ▶ Change to funeral homes and care in hospitals by strangers.

(Freeman, 2015)



- ▶ Technology focused on cure so care of dying never addressed
- ▶ Humanity and ethics did not keep current with technology.
- ▶ The cure focused medical model does not work for the terminally ill and dying – it must be person centered.
- ▶ IOM 2012 study found care of dying in America remains poor.
- ▶ Feelings of abandonment, loss of dignity, and expected suffering.

(Freeman, 2015)



- Care of the dying may not be high-tech, but it is definitely high-touch and deserving of treatment as an acute event. (Quill, 1998)
- The communication and high-touch skills required for quality end of life (EOL) care requires an emphasis in compassion, empathy, and acceptance of individual grieving processes and needs. (Ferrell & Coyle, 2010)

ESTABLISHING AN ACUTE EVENT

- ▶ 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.
- ▶ **NURSES MUST BE 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)

OVERCOMING BARRIERS TO PROVIDING QUALITY EOL CARE

- ▶ Take core education through ELNEC.
- ▶ Consider HPNA certification.
- ▶ Complete your own Advance Directive.
- ▶ Learn about Hospice/Palliative Care services
- ▶ Be a role model for other medical staff.

(Freeman, 2015)



BASIC PHYSIOLOGY OF DYING

Oxygen Deprivation

- ▶ Vascular occlusion from trauma, tumor, obstruction
- ▶ Loss of ability to transport oxygen
 - ▶ RBCs deficient production/dysfunctional/loss
 - ▶ Lung disease- loss of ability to pull in oxygen
 - ▶ Cardiac disease- loss of ability to circulate oxygen

(Edmonds, 2009)

CELLULAR DEATH/ORGAN FAILURE

Organs are highly sensitive to loss of oxygen, perfusion pressure, and resultant exposure to toxins/waste products

- ▶ Progressive liver failure
- ▶ Kidneys fail and lose ability to filter toxins
- ▶ Cerebral dysfunction
 - ▶ confusion
 - ▶ changes in LOC
 - ▶ Loss of temperature regulation

(Edmonds, 2009)



- ▶ Reduced/ loss of perfusion most distal from heart
 - ▶ Body struggles to perfuse heart, lungs, and brain
 - ▶ Vascular constriction
 - ▶ Extremities distal to proximal
 - ▶ Loss of GI tissue perfusion

(Edmonds, 2009)



- ▶ Loss of GI perfusion
 - ▶ Loss of appetite
 - ▶ Endorphins released
 - ▶ Cannot metabolize food
 - ▶ What little they can will feed disease/cancer
 - ▶ Cannot absorb – diarrhea/aspirate
- ▶ Malnourished, loss of COP
 - ▶ 3rd spacing/edema
 - ▶ pulmonary edema (Edmonds, 2009)



- ▶ Heart works harder to compensate
 - ▶ Reduced/loss of oxygen- heart failure
 - ▶ Focus on perfusing brain
- ▶ All systems begin to fail
- ▶ Loss of ability to swallow see pooling of oropharyngeal secretions
- ▶ Loss of cognitive function reduced to brainstem function

(Edmonds, 2009)



- ▶ Agitated to somnolent
- ▶ Death Rattle, increasing oropharyngeal secretions
- ▶ Loss of reflexes, pupils fixed and dilated
- ▶ Eyes may remain open
- ▶ Agonal mouth breathing
- ▶ Irregular respirations with apnea
- ▶ Mottled and cold extremities
- ▶ Loss of urine out-put
- ▶ Loss of bowel function (Edmonds, 2009)



FINAL HOURS

https://www.youtube.com/results?search_query=the+body-Death-Dying

BODY STORY: DEATH & DYING



- ▶ Provide reassurance and education
- ▶ Need to tell difference between suffering and normal course of dying.
- ▶ Help with acute grief
 - ▶ Focus on what patient was like
 - ▶ Encourage discussions about memories
 - ▶ Actively Listen
- ▶ Encourage Family members to:
 - ▶ Take breaks
 - ▶ Eat/ provide grieving cart
 - ▶ Offer to assist with final arrangements
- ▶ Obtain assistance from Palliative Care team members



(Freeman, 2015)

FOCUS ON FAMILY

- ▶ Pain Management for the Dying
- ▶ Communication
- ▶ Emphasis on Self-Care
- ▶ Basis of the CARES Tool



PART I: IMPORTANT CONCEPTS

- ▶ If pain before unresponsive, consider still in pain.
- ▶ There will always be a last dose.
- ▶ Concept of intent.
- ▶ No dose limits.
- ▶ Addiction issues don't apply.
- ▶ Use of long acting and break through opioids.
- ▶ Patient's will die faster if in pain.
- ▶ Be aware of who you are really taking care of.
- ▶ Rely on family to help assess pain.

(Freeman, 2015)



IMPORTANT POINTS ON PAIN MANAGEMENT

- ▶ Consider rotating opioids if side effects or ineffective.
- ▶ Fentanyl best with renal failure and if myoclonus occurs.
- ▶ Use PCAs and adjust basal rate as needed and use RN bolus.
- ▶ Remain available to family and check in frequently.
- ▶ Remember patient is actively dying and they are most likely to die from their disease than the opioid they were given.
- ▶ Encourage family involvement, calming voices, and music.
- ▶ Educate
- ▶ Anything you can give orally, you can give rectally. (Freeman, 2015)

PAIN MANAGEMENT



COMMUNICATION



THE ELEPHANT IN THE ROOM

**There is a reason we have two ears and
one mouth.** (Annonomyus)

A decorative graphic consisting of several parallel white lines of varying lengths, slanted diagonally from the bottom right towards the top right, located in the lower right quadrant of the image.



EMPHASIS ON SELF-CARE

- We must acknowledge the personal responsibility we have to care for ourselves.
- Communication is just as important between you and co-workers as it is between you and your patients.
- We all need to feel we are being listened to, appreciated, and respected.
- Our perceived failures must be addressed.
- Burn out is the last straw, it must be addressed early before it grows.

(Wicks, 2006)

PERSONAL RESPONSIBILITY

“The seeds of burnout and the seeds of enthusiasm are in reality the same seeds, anyone who truly cares can expect to ride the waves of burnout- and occasionally get knocked down by a wave they missed.”

(Wicks, 2006, p.26)







Anton Chekov once proclaimed:

“Any idiot can face a crisis- it’s the day-to-day living that wears you out.” (Wicks, 2006)



“If the temperature of the bath rises one degree every ten minutes, how will the bather know when to scream?” (Wicks,2006)



- ▶ Ability to empathize is essential
 - ▶ Must see ourselves in our patients
 - ▶ Forces us to confront our vulnerability
 - ▶ Forces us to acknowledge statistical likelihood

Recognize our vulnerability.

- ▶ Appreciate the daily wear and tear of patient interactions.
- ▶ Providing holistic patient care is as physically and emotionally depleting as the disease is to a patient.
- ▶ Make time for rest, restoration, and rejuvenation of body and spirit.

(Wicks, 2006)



BECOME SELF-AWARE

- Do not believe the pedestal you have been 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. (Wicks, 2006 & Freeman, 2015)

SELF CARE PEARLS

- 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. (Wicks, 2006 & Freeman, 2015)

SELF-CARE PEARLS (CONT)



FIND YOUR JOY

- ▶ When was the last time you:
- DANCED
- SANG
- LAUGHED
- Did something artistic
- Did something just for you
- Slept more than 8 hours

(Freeman, 2015 & Wicks, 2006)

BREAK

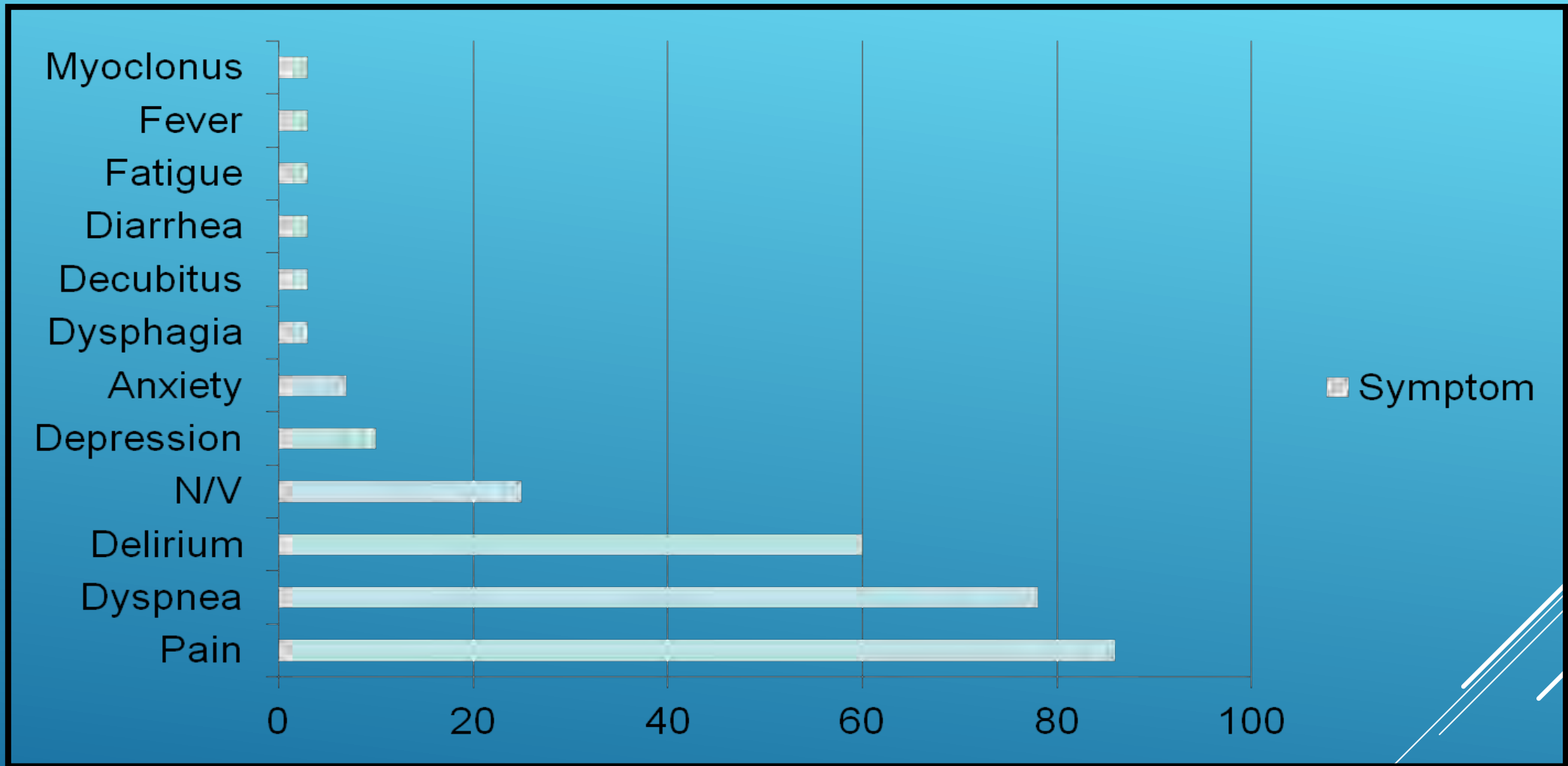


COMPASSIONATE PERSON-CENTERED CARE OF THE DYING

PART II: THE CARES TOOL

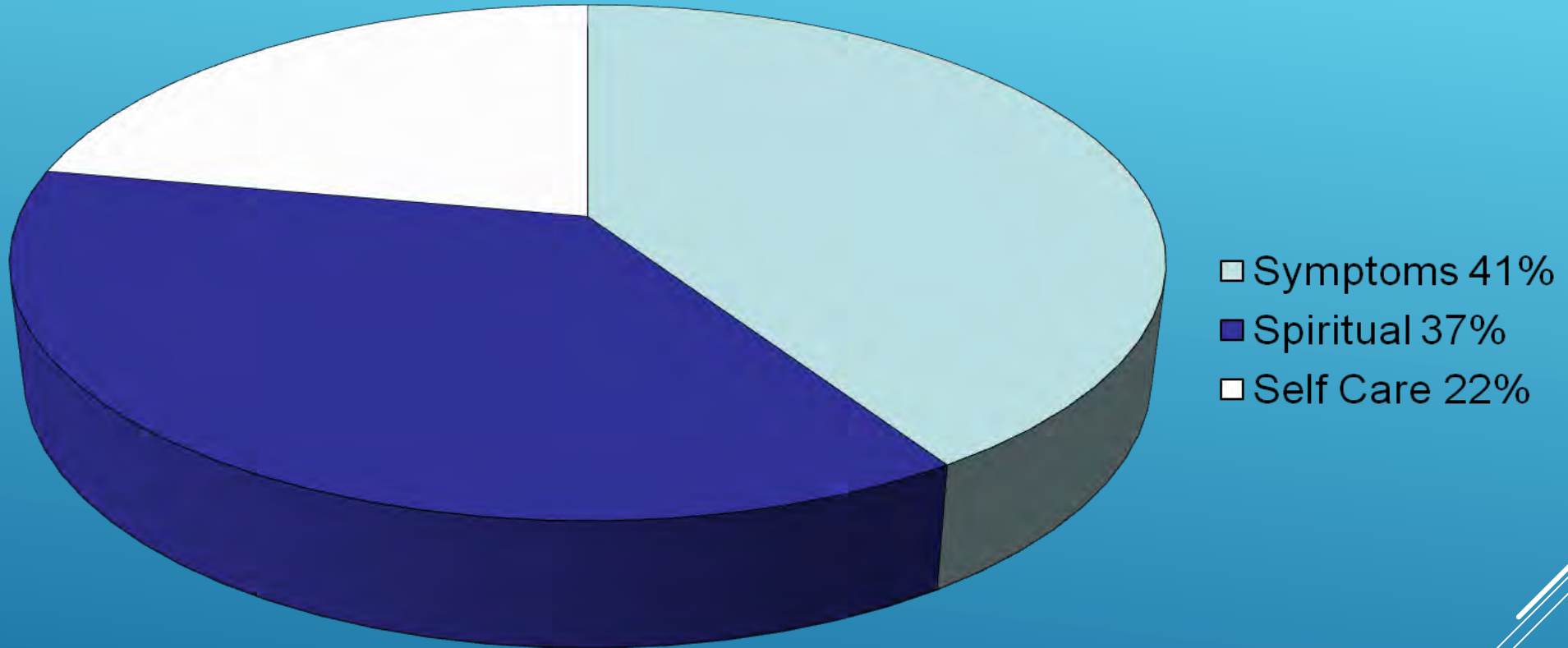
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SYMPTOM MANAGEMENT NEEDS OF THE DYING (FREEMAN, 2013)

Based on 68 Studies



COMMON NEEDS OF THE DYING (FREEMAN, 2013)

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)

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, B. (2013). CARES: An acronym organized tool for the care dying.

Journal of Hospice & Palliative Nursing, 15(3), 147-153.

<http://www.medscape.com/viewarticle/803156>





COMFORT

- Pain was the most common symptom management need of the dying.
- Individuals do not fear death as much as how they will die.
- 90-50% of patients will die in pain (LeGrand & Walsh, 2011).
 - Lack of education
 - Fear of euthanasia
 - Cultural factors
 - Fear of addiction
 - Fear of speeding up dying process

(Freeman, 2015)

- Act as a patient advocate.
- 90% of patients die in pain (LeGrand & Walsh, 2011).
- 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.

(Quill, 1998; Byock, 2012).



THE FOCUS OF CARE IS COMFORT

Evaluate need for procedures, tests and activities.

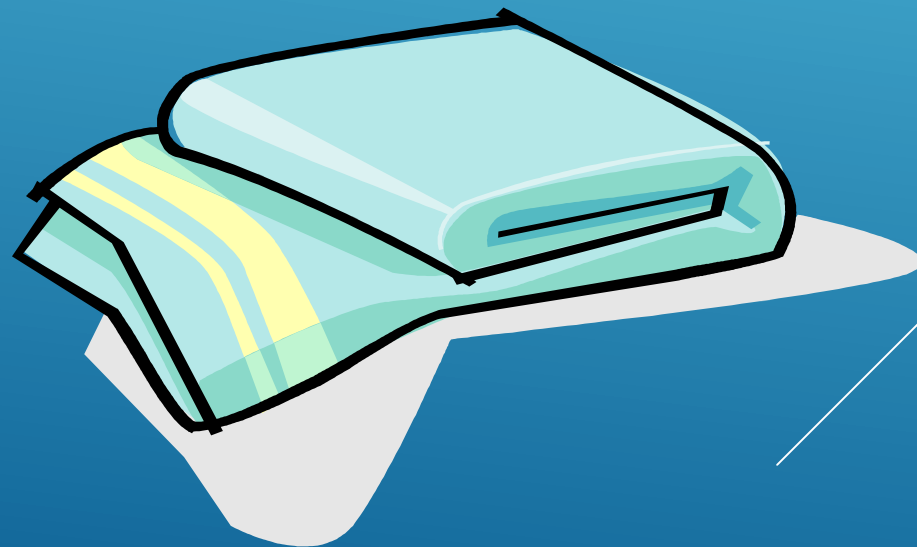
Provide as much time for the patient and family to be together as possible. (Ferrell & Coyle, 2010)

- 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)



- **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)



- ▶ Oral suctioning is ineffective and usually just stimulates secretion production.
 - ▶ Can be an activity for the family if requested.
 - ▶ Explain that the agonal and irregular respirations are the best the body can do as it prepares to shut down.
 - ▶ Control “death rattle”
 - ▶ Scopolamine
 - ▶ Robinul
 - ▶ Atropine eye gtts given oral (Freeman, 2015)
- 

- ▶ Consider O₂ at 2lit/min if family requests
- ▶ Position to comfort and optimal oral drainage.
- ▶ Family will need frequent reassurance that patient is not suffering.
- ▶ Much of your education will need to be repeated as individuals cannot retain information when stressed.
- ▶ Titrate morphine up as a trial to see if respiratory effort can be lessened.

(Freeman, 2015)



RESTLESSNESS AND DELIRIUM

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

(Ferrell & Coyle, 2010)

Educate the family:

- Patient lacks awareness of behavior.
- Possible to be peacefully confused.

(Freeman, 2015)



Also called terminal or agitated delirium.

Consider:

- ▶ Trial dose of opioids- pain is the most common cause of delirium
- ▶ antipsychotics: haloperidol or chlorpromazine.
- ▶ benzodiazepines: Lorazepam or Midazolam.
- ▶ Playing favorite music
- ▶ Have favorite smells
- ▶ Have family members talk reassuringly
- ▶ Minimize stimulation
- ▶ Have family give permission

(Freeman, 2015)

- ▶ Educate the family:
 - ▶ Patient lacks awareness of behavior.
 - ▶ Possible to be peacefully confused.
 - ▶ Brain cells are dying due to lack of oxygen and circulating toxins from liver and organ failure.
 - ▶ Common for the dying to see/talk to others who have died.
- ▶ Assist with any religious rituals/ beliefs/ concerns of an after-life
 - ▶ Obtain support from Spiritual Care

(Freeman, 2015)

Let Grandma Stay in the Bahamas





EMOTIONAL AND SPIRITUAL SUPPORT

- **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.**



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)



**Celebrate the Person.
They are NOT their disease.**

(Freeman, 2015)



SELF-CARE

- **Allow yourself to be human.**
- Professional grieving
 - Its 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.



- Find ways to positively vent and promote communication.
- Give genuine compliments.
- Seek creative solutions to problems.
- Help others in need.
- Utilize humor daily.
- Emphasize the importance of having joy in your life.
- Take breaks off the unit/work area.
- Show appreciation for others. (Wicks, 2006)

CONSTRUCTIVE APPROACHES TO MINIMIZE SOUL INJURY

Sharing insight about our sadness and loss can help find meaning and allow for personal growth. Just putting your feelings into words can be healing. *(Wicks, 2006)*

IMPORTANCE OF DEBRIEFING

- Do not believe the pedestal you have been 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.
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SELF-CARE PEARLS (CONT)

“...When all of life – both the perceived good and bad is faced directly with a sense of openness, life’s promises are more fully realized. Moreover, this is not only important for the person experiencing the struggles but also for those they may touch after absorbing the new lessons learned about gratitude, impermanence, the frailty of life, simplicity, meaning-making, and compassion.” (Wicks, 2006)

“If we can learn to ride our dragons rather than run, hide from, or attack them, it can be transforming.” (Wicks, 2006)

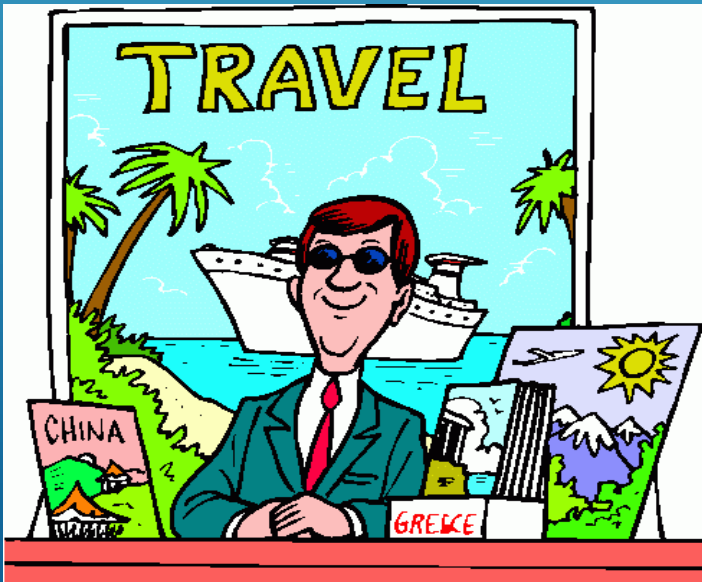


- Self care must include mindfulness and self-awareness of the baggage we all carry.
- Daily stressors add up like scalding water in a bath and we don't know when to scream.
- Group support, staying present, and accepting the limitations of care a nurse can provide can all assist in maintaining personal resiliency.
- We all need to stop running from the emotional pain caring for the dying can cause, and chose to **"Ride the Dragon"**.
- If we are open to learn from our experiences and embrace the journey we can:
 - Learn about and embrace our personal strengths.
 - Understand how helplessness and loss can be faced with dignity.
 - Embrace how being vulnerable can open us up to self-acceptance.
 - Appreciate how humility can be the very door that leads to compassion.

(Wicks, 2006)

SELF-CARE CONCLUSIONS

- ▶ 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.

RESOURCES

**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>

RESOURCES

- American Medical Association (AMA). (2012). *The EPEC Project (Education in Palliative and End of Life Care)*. Retrieved from <http://www.epec.net>
- Byock, I. (2012). *The best care possible: A physician's quest to transform care through end of life*. New York, NY: Avery.
- Dickenson, G. (2007). End-of-life and palliative care issues in medical and nursing schools in the United States. *Death Studies, 31*, 713-726.
- Edmonds, M. (2009). How Suff Works. Retrieved from: <http://health.howstuffworks.com/diseases-conditions/death-dying/dying3.htm>.
- Ferrell, B. R., & Coyle, N. (Eds.). (2010). *Oxford textbook of palliative nursing (3rd ed.)*. New York, NY: Oxford University Press.
- Freeman, B. (2015). *Compassionate Person-Centered Care for the Dying: An Evidence-Based palliative Care Guide for Nurses*. New York: Springer Publishing Co.
- Freeman, B.J. (2013). *The CARES Tool: Development and Application*. DNP Translational Project, Azusa :CA, Azusa Pacific University.
- LeGrand, S. B., & Walsh, D. (2011). Comfort measures: Practical care of the dying cancer patient. *American Journal of Hospice and Palliative Medicine, 27*, 488-493.

REFERENCES

Ong, W., Yee, C. M., & Lee, A. (2012). Ethical dilemmas in the care of cancer patients near the end of life. *Singapore Medical Journal*, 53(1), 11-14.

Puchalski, C. M., & Ferrell, B. R. (2010). *Making healthcare whole: Integrating spirituality into patient care*. West Conshohocken, PA: Templeton Press.

Quill, T. E. (1998). Principal of double effect and end-of-life pain management: Additional myths and a limited role. *Journal of Palliative Medicine*, 1, 333-336.

Thurston, A.J.; Wilson, D.M.; & Hewitt, J.A. (2011). Current end of life care needs and care practices in acute care hospitals. *Nursing Research and Practice*, 2011: 1-8.

Whitbourne, S. K. , & Whitbourne, S. (2011). *Adult development and aging: Biopsychosocial perspectives* (4th ed.). Hoboken, NJ: John Wiley & Sons.

Wicks, R. (2006). *Overcoming Secondary Stress in Medical and Nursing Practice: A Guide to Professional Resilience and Personal Well-Being*. New York: Oxford University Press

REFERENCES

PART III: GROUP DISCUSSION



The End of Life

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DEATH IS NOT
CONTAGIOUS
BUT IT IS
INEVITABLE

WE ARE ALL
HUMAN

OPEN
DISCUSSION

CARES

Application Game

CARES Scenerio

Geri Adams is a 72 year old female with end stage pulmonary fibrosis admitted for increasing shortness of breath, dysphagia, and chronic back pain that has become more severe in the past week. Husband is crying stating, “I just can’t take care of her anymore.” Geri is tearful and anxious. She is on a high-flow mask at 100%, and has not discussed her wishes for code status. Palliative Care was consulted to discuss goals of care and for symptom management.

Misc. Info:

- ▣ MD: Just don't let her suffer
- ▣ Has a 28 year old daughter that she recently re-established connection with, and who is planning to marry next month.
- ▣ Devout Southern Baptist
- ▣ Loves her cat Missey

Sample of a Comfort Care Order Set Based on CARES Tool

General Orders:

- ❑ Confirm DNR/DNI code status (AND)
- ❑ Review Comfort Care order set with family
- ❑ Confirm with Infection Disease Dept. that isolation can be cancelled for family members.
- ❑ Support and provide 24 hour visitation
- ❑ Turn q2 hr/prn for comfort with family's permission
- ❑ Provide diet as tolerated
- ❑ Contact Cardiology re: turning off Pacemaker and/or Implanted Cardiac Defibrillator.
- ❑ Bathe only with family's permission
- ❑ Provide cooling /comfort measures such as ice packs, cooling blanket, wash cloths etc.
- ❑ Reinforce dressings only
- ❑ Maintain one IV at 10ml/hr for vascular access and discontinue all other IVs and IVPBs.
- ❑ Reduce vital signs to every shift and prn.
- ❑ Order/provide grieving cart.

Discontinue:

- Lab work, glucose finger sticks, and blood cultures
- PT, OT,
- Daily weights
- IV antibiotics and antifungals
- All blood products
- All oral medications not directed at maintaining comfort- clarify with provider.
- Tube feedings
- TPN
- Monitors and telemetry
- Sequential pressure devices
- Breathing treatments
- Dialysis
- Imaging studies

Consult:

- Supportive Medicine
- Child Life Specialist
- Psychiatry
- Psychology
- Social work
- Spiritual care
- Hospice

General Medications:

- Acetaminophen 650mg elixir or suppository q4hrs prn temperature >104 F
- Artificial tears 2 gtts both eyes q2hrs prn dry eyes or discomfort.
- Saline spray 1 spray to each nare prn dryness or discomfort.
- Ondansetron 4-6mg po/sub ling q6hrs prn nausea/vomiting. Max: 32mg/24hrs.
- Reglan 10mg IV/sub-cut q 6hrs prn if Ondansetron ineffective or patient is intolerant.
- Scopolamine 1.5mg/72hr transdermal behind the ear, nausea/vomiting/excessive secretions.
- Relistor 8mg sub cut q 3 days prn constipation.
- Lorazepam 0.5-1mg q4hrs IV/Sub-cut q4hrs prn nausea/anxiety/restlessness.
- Lorazepam 1mg po/sub-ling q4hrs prn nausea/anxiety/restlessness.
- Lorazepam continuous IV/Sub-cut at _____ mg/hr, increase to a maximum of _____ mg/hr then contact MD for additional dosing orders.
Benzodiazepine naïve patients should be started at 0.5-2mg IV/Sub-cut q1hr.
Increase by 50% q 15min prn.
- Haloperidol _____mg IV/Sub-cut q _____ hrs prn nausea/anxiety/restlessness.
0.5-1mg IV q4hrs prn If less than 60kg and over 70 years of age.
1-2mg IVq4hrs prn if greater than 60kg and less than 70 years of age.
Maximum of 100mg/24hours then contact MD for additional dosing orders.
- Midazolam _____ mg IV/Sub-cut then start continuous IV/Sub-cut infusion at _____ mg/hrs prn anxiety/restlessness and titrate up q _____ to a maximum of _____mg/hr then contact MD for additional dosing orders.
1-2mg/kg bolus IV/Sub cut loading dose
0.5-5mg/hr or 25% of loading dose.

Pain Management:

- See orders for PCA :
Start at IV equivalent of 24 hour opioid usage and increase by 50% q15 minutes prn.
For opioid naïve patients consider:
Morphine Sulfate 2-5mg/hr (Recommended unless intolerant or renal failure)
Hydromorphone 0.5-1mg/hr
Fentanyl 20-50mcg/hr
- Increase PCA basal rate by _____ q 15 minutes for pain and restlessness. **(Rapid rate of titration for patients approaching end of life is of paramount importance.)**
- Provide RN bolus of _____ every 5 minutes prn (See PCA orders).
- May convert PCA to sub cutaneous if IV access lost (Maximum 3cc/hr). Contact Pharmacy for concentration recommendations and notify MD for orders.
- See medication orders:
Provide po opioids sublingually if patient unable to swallow.
For opioid naïve patients consider:
Morphine (20mg/ml) 5mg-15mg po/sub-ling q1hr prn
Oxycodone (20mg/ml) 5-10mg po/sub-ling q1hr prn

Airway Management:

- Obtain disposable fan and set to low. Position to blow toward either side of patient's face,
- Provide supplemental oxygen of _____ (2lit/min per nasal cannula recommended).
- Oral suction prn, avoid deep suctioning.
- Reposition prn to promote ease of breathing.
- Provide oral care and moisturize lips with water-base lip balm prn.
- Albuterol 2.5mg/normal saline 3ml via nebulizer q1hr prn wheezing
- Robinul (Glycopyrrolate) _____mg IV/Sub-cut q_____ hr prn increased oral secretions.
0.4-1mg IV/Sub-cut q1-4 hrs prn
Recommend: start at 0.4 IV/Sub-cut q 4hrs prn and increase dosage and frequency prn to a maximum of 1mg IV/Sub-cut q 1 hr prn.
- Atropine 1% ophthalmic solution 2 gtts sub ling q 1hr prn excessive oropharyngeal secretions.
- Levsin (Hyoscyamine) _____mg q_____ hrs prn excessive oropharyngeal secretions.
0.125-0.25 mg sublingually q 4 hrs prn
Recommend to start at 0.125mg subling q4hrs prn and increase dosage and frequency prn to a maximum of 0.2mg subling q 1 hr prn.
- Scopolamine patches 1.5mg/72hr transdermal for excessive secretions if not already ordered.

Delirium Management:

- Give trial dose of opioid ordered for pain to rule-out pain component of delirium.
- Assess for bladder distention and insert catheter into bladder if patient has not voided in 8 hours. Connect catheter to gravity drainage if urine output is greater than _____cc.
- Chlorpromazine _____ mg IV/sub-cut q_____ hrs prn, increase q_____ to a maximum of _____ mg/hr then contact MD for further adjustments in dose.
 - 25mg IV/Sub-cut initial dose
 - 25-50 mg IV/Sub-cut q4hrs prn agitation/delirium
 - Increase dose to a maximum of 50mg IV/Sub-cut q1hrprn or as a continuous IV infusion.
 - 2000mg maximum 24 hour total dose.
- See previous General Medication orders.
- Provide calming environment with family's input such as:
 - Lowering lights
 - Playing patient's favorite music
 - Ask family/ assist to provide favorite smells
 - Reduce background noise and interruptions.
 - Encourage use of touch and presence.

Nursing Comfort Orders

- Review CARES Tools and contact Supportive Care with any questions.
- Provide CARES Tool for Family and Friends version to patient's visitors.
- Encourage family involvement in patient care to their level of comfort.
- Lower side rails if family members remain in room, and place chairs at sides of bed.
- Maintain presence and continue to educate as appropriate.
 - Explain the need for and assist family with closure statements such as saying good-bye and giving permission.
 - Help family to differentiate between a normal dying course and suffering.
 - Provide general physiology of the dying process.
 - Provide additional supportive literature.
- Insure communication exists between all parties involved in care.
 - Take cues from family
 - Establish family preferred chain of communication.
 - Clarify how much the patient and family wants to know.
 - Help arrange family meetings as directed/requested.
 - Confirm goals of care are current.
 - Clarify and follow through on providing family privacy needs.
 - Be sensitive to patient and family's perceived sense of abandonment.
 - Support rituals requested by the family.