

# The Navigator's Role in Integrating Palliative and Supportive Care

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# Disclosure Statement

The presenter of this lecture has no relationship with industry or any commercial interests that might affect their presentation, and therefore have nothing to disclose.

# Objectives:

- Define Palliative Care as it pertains to patients diagnosed with cancer and provide best practices for discussion and implementation in the navigation/care coordination process.
- Utilize best practice strategies related to care given to improve quality of life for patients with cancer undergoing treatment, post treatment, and end of life.
- Discuss basic symptom management needs of cancer patients to include treatment for chemotherapy induced nausea and vomiting.
- Emphasize the importance of being a strong patient advocate throughout a patient's disease process.

# Definitions:

**Palliative Care:** Patient-family centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice. (Dahlin, Coyne, & Ferrell, 2016)

**Nurse Navigator:** A specially trained advanced practice Oncology Nurse that provides assistance to patients, families, and caregivers to help them overcome healthcare system barriers and to facilitate timely access to quality health and psychosocial care from pre-diagnosis through all phases of the cancer experience. (ONS, 2013)

# General Principles of Palliative Care

- Patient and family as unit of care.
- Attention to physical, psychological, social and spiritual needs.
- Interdisciplinary team approach
- Promote communication.
- Education and support of patient and family.
- Extends across illnesses and settings.
- Provide additional support/ recommendations for symptom management.

# Comparison: Nurse Navigators and Palliative Care NP (ONS, 2013)

| Duties/Responsibilities                                 | Nurse Navigators | Palliative Care Nurses | Comments |
|---|------------------|------------------------|----------|
| Provide emotional and educational support               | X                | X                      |          |
| Practice according to professional and legal standards. | X                | X                      |          |
| Advocate on behalf of the patient.                      | X                | X                      |          |
| Demonstrate ethical principals in practice.             | X                | X                      |          |
| Orient patients to cancer care system.                  | X                |                        |          |
| Receive and respond to new patient referrals            | X                | X                      |          |
| Pursue Oncology related education activities            | X                | X                      |          |
| Collaborate with other healthcare providers             | X                | X                      |          |
| Empower patients to self-advocate                       | X                | X                      |          |
| Assist patients to make informed decisions              | X                | X                      |          |
|   |                  |                        |          |

# Skills Comparison (ONS, 2013)

| <b>Skills</b>  | <b>Nurse Navigators</b> | <b>Palliative Care Nurses</b> |
|--|-------------------------|-------------------------------|
| Strong communication skills both written & verbal                  | X                       | X                             |
| Good analytical and deduction skills                               | X                       | X                             |
| Need to be sympathetic and provide emotional support               | X                       | X                             |
| Organized and able to multi-task                                   | X                       | X                             |
| Able to work in tough stressful condition with a positive attitude | X                       | X                             |

# Education and Requirements

(ONS, 2013)

| Education and requirements | Nurse Navigator | Nurse on PC Team | PC Nurse Practitioner |
|----------------------------|-----------------|------------------|-----------------------|
| BSN                        | X               | Preferred        |                       |
| MSN                        |                 |                  | X                     |
| NP Certification           |                 |                  | X                     |
| DNP                        |                 |                  | Preferred             |
| 2+ years RN experience     | X               | Preferred        | Preferred             |
| Health or Patient Educator | X               |                  |                       |
| Pharmaceutical rep         | X               |                  |                       |
| Certifications             | Preferred       | Preferred        | Preferred             |
| Pain mgmt skills           | X               | X                | X                     |
| Furnishing License         |                 |                  | X                     |
| DEA Certification          |                 |                  | Preferred             |



# Importance of Advocacy

- To insure goals set by the patient and their family are the basis of care.
- Promote communication.
- Be actively involved in symptom management.
- Promote and nurture transcendence and hope.
- Eliminate patient and family's fears of abandonment.
- Be therapeutically present. (Ferrell & Coyle, 2010)

# Comparison Scenarios

Ryan, a 40 year-old Caucasian male with a hx of metastatic gastric cancer to the lymph and pericardium. Now s/p large anterior wall MI

- Holistic and compassionate management.
- Basic symptom management needs.
- Possible resolutions.
- Need for person-centered EOL care.
- How to make a difference.
  - Listening
  - Communication

Marie, a 28-year-old Hispanic female with a history of metastatic ovarian cancer.

- Holistic and compassionate management.
- Basic symptom management needs.
- Possible resolutions.
- Need for person-centered EOL care.
- How to make a difference.
  - Listening
  - Communication

# The Power of Listening

I suspect that the most basic and powerful way to connect to another person is to **listen**. Perhaps the most important thing we ever give each other is our attention. And especially if it is given from the heart. When people are talking, there's no need to do anything but receive them. Just take them in. Listen to what they are saying. Care about it. Sometimes caring about it is even more important than understanding it

(Remen, 1966).

“A loving silence often has far more power to heal and to connect than the most well intentioned words.”

(Remen, 1966)

We all need **basic human kindness**-the reliable **presence** and love of another person, someone willing to be in regular contact with us for the duration of our journey through suffering. We need others to **simply listen** and **bear witness** to our pain, offering **support, encouragement, and honesty** tempered with **compassion**

(Longaker, 1995, p. 54).

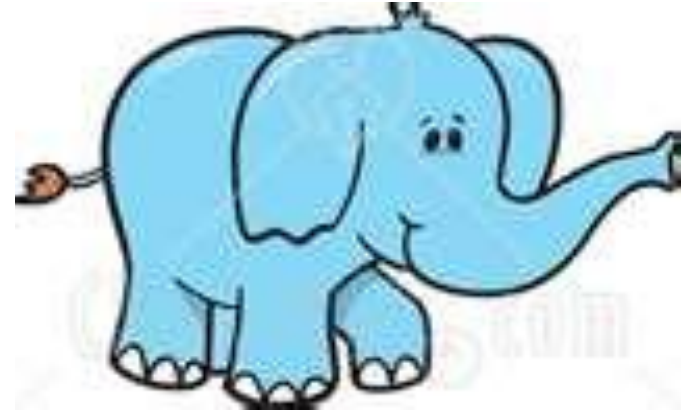
Persons and families must feel they are ***more than the disease they are fighting***. They must be allowed to keep their dignity and emotional strength intact so hope can evolve and be redefined.



(Ferrell & Coyle, 2010)

# Achieving Compassionate Communication

- Active Listening
- Honest and open responses
- Genuine caring
- Compassionate tone
- Clarifying
- Letting patient and family take the lead
- **Addressing the ELEPHANT IN THE ROOM**
- Therapeutic presence
- Avoiding sense of abandonment
- Helping to re-define hope



(Ferrell & Coyle, 2010; Wittenberg-Lyles, Goldsmith, Ferrell, & Ragan, 2013)



# Basic Symptom Management



## Rarely is Pain Ever Just Physical

Always consider:

- Psycho social implications
- Spiritual issues
- Cultural concerns

(Pasero & McCaffery, 2011)



# Pain Management

- Art and a science
- Complicated by insurance companies and government restrictions.
- Make a commitment to learn.
- Use of Cognitive Behavioral Therapies
- Interventional pain management resources
- Addiction vs tolerance
- Use of your humanity (Ferrell & Coyle, 2010)

# Constipation

- Only opioid side effect that the body does not build a tolerance to over time.
- Set limits adjusted to patients normal routine.
- Use a stimulant + a softener like Senna S
- The sweetener sugar alcohol, used in sugar free products is a natural laxative.
- Have patients explore laxative counter.
- Miralax
- Lactulose
- Relistor/ Methylnaltrexone (8mg/0.4ml vial) sub-cut
- Diet
- Exercise

(AAHPM, 2014)

# Nausea and Vomiting

- Consider receptor site
  - **Cortex:** sensory input
  - **Vestibular System:** motion
  - **Chemoreceptor trigger:** drugs and products of metabolism, bacterial toxins, hyponatremia, and hypercalcemia
  - **Peripheral Pathways:** mechanical stretch from GI distention/obstruction, infection, radiation, GERD, local toxins, chemo

(AAHPM, 2014)

| Receptor   | Cause  | Medication  |
|--|--|---|
| <b>Cortex</b>  | Sensory input, anxiety, CNS tumors, meningeal irritation, pain, increased ICP            | <b>Central Acting:</b><br>Dexamethasone Lorazepam   |
| <b>Vestibular</b><br>(ACH, H1)                                 | Motion sickness, labyrinth disorders, middle ear infections.                             | <b>Acetylcholine Agonists</b> (ACH):<br>Diphenhydramine and Scopolamine<br><b>Histamine Antagonists</b> (H1):<br>Diphenhydramine, Meclizine and Hydroxyzine                   |
| <b>Chemo Trigger</b><br>(5HT3, Dopa2, NK1)                     | Drugs, metabolic products, hyponatremia, hypercalcemia, bacterial toxins                 | <b>Serotonin Agonists</b> (5HT3, NK1):<br>Ondansetron<br><b>Dopamine Agonists</b> (dopa2):<br>Haloperidol<br>Metaclopramide<br>Prochlorperazine<br>Promethazine<br>Olanzapine |
| <b>Peripheral Pathways</b><br>(5HT3, mechano & chemoreceptors) | Mechanical stretch, GI mucosal injury etc: radiation, toxins, tumors, drugs, infections. | <b>Serotonin Agonists</b> (5HT3):<br>Ondansetron<br><b>Inoperable Obstruction:</b><br>Octreotide<br><br>(AAHPM, 2014)   |

# Anti-Emetic Infusion

(AAHPM, 2014)

| Drug            | 24 hour dose SC/IV |
|-----------------|--------------------|
| Dexamethasone   | 2-20mg             |
| Diphenhydramine | 25-100mg           |
| Famotidine      | 20-40mg            |
| Haloperidol     | 2-10mg             |
| Midazolam       | 2-12mg             |
| Metoclopramide  | 40-120mg           |
| Octreotide      | 300-1200mcg        |
| Ondansetron     | 4-32mg             |

# Anxiety and Depression

- Treatable even with Hospice patients
- Impairs quality of life
- Often not a clear psychosocial trigger
- Risk Factors:
  - Cancer
  - Metabolic disorders
  - Alzheimer's
  - Parkinson's
  - Poor pain or symptom control
  - Medications
  - Personal or family history
  - Poor social support
  - Financial strain

(AAHPM, 2014)



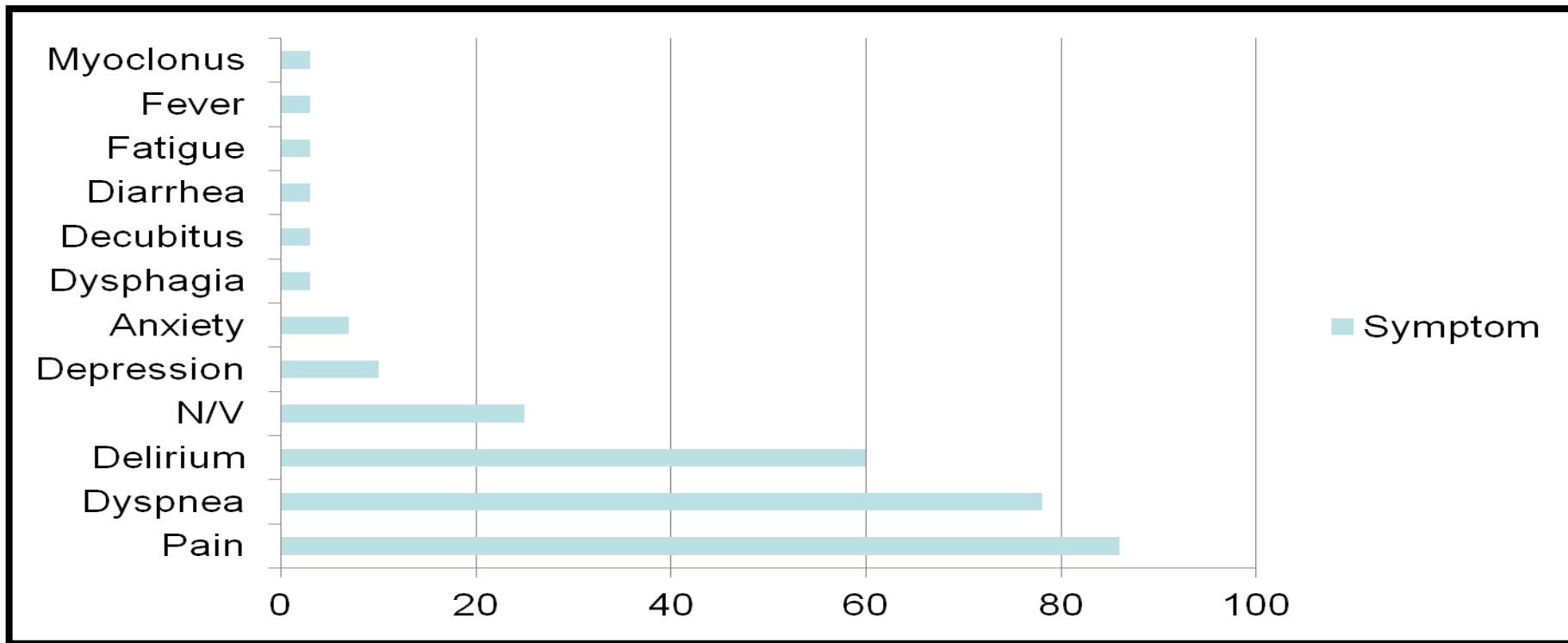
# End of Life Care



# Symptom Management Needs of the Dying

(Freeman, 2015)

OncologyNurseAdvisor  
navigation  
SUMMIT



# The CARES Tool Organization and Considerations

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

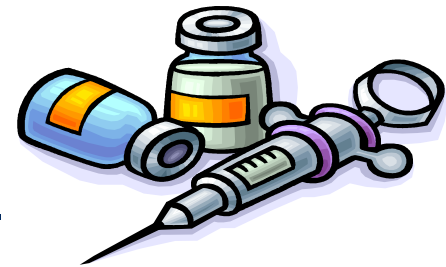
- **C**omfort
- **A**irway
- **R**estlessness and delirium
- **E**motional and spiritual support,
- **S**elf-care.

(Freeman, 2015)



- Act as a patient advocate.
- 90% of patient's die in pain (LeGrand & Walsh, 2011).
- If they were in pain before 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.

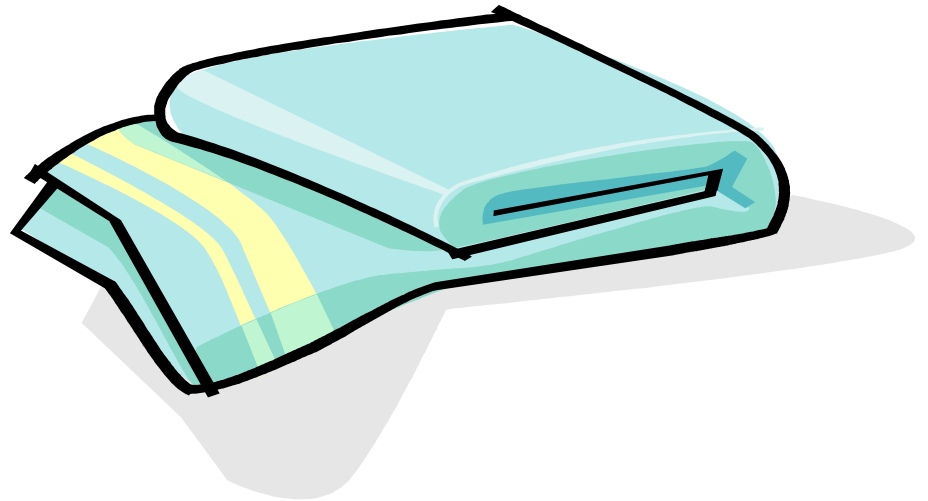
(Ferrell & Coyle, 2010)

- 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.



- **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)



- SOB 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

- R/O treatable causes
- 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.



# Emotional and Spiritual Support

**Just be** with patient and family.

Work with family to provide favorite activities

Support rituals.

**Your humanity is needed the most.**

**Always be available.**

The **family** becomes your focus

- Be sure families are getting rest and bi
- Provide coffee, water, etc.
- Continue to be available to answer questions.



(Ferrell & Coyle, 2010)

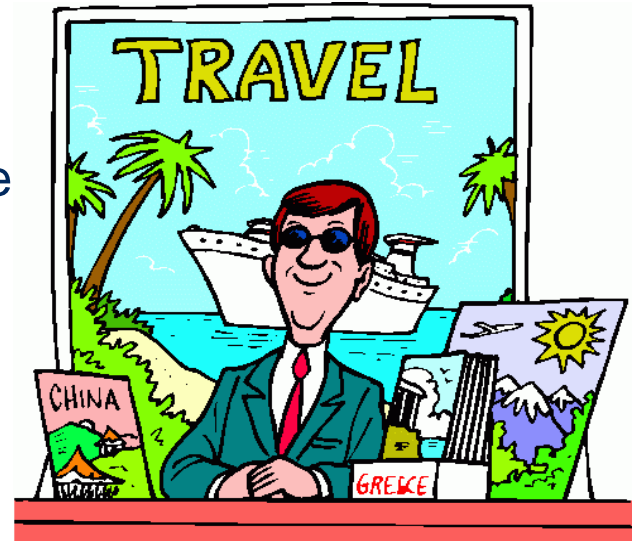
# It's All About the Journey

We cannot change the fact a patient will become terminally ill or die, but we have everything to say about **THE JOURNEY**.

- Be pro-active and anticipate.
- Request Palliative Care consults.
- Celebrate the person- they are not their disease



(Freeman, 2015)



# Self-Care Pearls

(FREEMAN, 2015, & Wicks, 2005)

- **Be realistic**, don't believe the pedestal you were placed upon.
- You are **not all-knowing** or all-powerful.
- Acknowledge that a **power greater than yourself** will ultimately determine the fate of the individual.
- Find comfort in knowing **you did your very best**.
- Learn to **celebrate the journey** and the opportunity.
- Identify parallels or issues about death causing **over-identification**.
- Stay in the now and **separate personal issues** from what actually happened.
- Take the time to **identify, explore, and work through personal issues** that surfaced.
- **Personal growth** occurs best when the heart is most broken.



“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).

## **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](http://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>

# Supportive Care Materials at City of Hope

Website: <https://www.cityofhope.org/homepage>

- Click on Education
- Click on Health professional Education
- Select Supportive Care Medicine from the selection box
- Select CARES Program from new Selection box
- Now you can access all components of the CARES Tool
  - Provider /original version
  - Supportive Hospital Staff Version
  - EOL VERSION: Final Journey
  - Self-care poster
  - Comfort order set



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