

MANAGEMENT OF NON-PAIN CONDITIONS AND GRIEF

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PROGRAM DETAILS

- **Title:** Management of Non-Pain Conditions and Grief
- **Dates/Term of offering:** This activity was released on June 17, 2026 and is valid for one year. Requests for credit must be made no later than June 16, 2027.
- **Joint Providership:** This activity is jointly provided by Global Education Group (Global) and Hospice and Palliative Board Review.com.



- **Target Audience:** The educational design of this activity addresses the needs of Physicians, NPs, Nurses, and health care professionals interested in learning more about hospice and palliative medicine and those who want to earn continuing education credits and/or prepare for board certification in hospice and palliative medicine.

PROGRAM DETAILS

- **Program Overview:** Clinicians and health care professionals are unaware of best practices to be utilized when triaging and referring eligible patients to ensure appropriate hospice and palliative care utilization. As such, they do not know how to adequately refer and counsel patients & families on appropriate utilization of hospice and palliative care services.

- **Faculty:** Eric Bush, MD, RPh, MBA, CHCQM; CEO- Hospiceandpalliativeboardreview.com-Board Certified Internal Medicine, Hospice and Palliative Medicine, and Addiction Medicine

- **Physician Accreditation Statement:**

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PROGRAM DETAILS

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- **Instructions to Receive Credit:** In order to receive credit for this activity, the participant must score at least a 75% on the post quiz and submit a completed evaluation and credit application form.

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- **Fee Information & Refund Policy:** There is a fee for this educational activity. For refund details, please see <https://hospiceandpalliativeboardreview.com/refund-policy/>.

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The ***faculty*** have the following relevant financial relationships with ineligible companies:

- **Eric Bush, MD, RPh, MBA:** Nothing to disclose
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PROGRAM DETAILS

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LEARNING OBJECTIVES

- Describe how to perform symptom management in the palliative and hospice setting.
- Describe how to counsel patients and caregivers on interventions in this setting and the applicable risk versus benefit for appropriate interventions.
- Describe how to perform discussions of US hospice regulations with patients and family.
- Describe how to counsel patients and caregivers on US hospice regulations and appropriate care for the patient and family given current regulations.
- Describe how to perform discussions differentiating between hospice and palliative care services with patients and family.
- Describe how to counsel patients and caregivers on differentiating between hospice and palliative care services and appropriate level of care for the patient and family given current best practice.

PALLIATIVE CARE AND SYMPTOM MANAGEMENT

Palliative Care is next

Focus outline can be found on page 122

PALLIATIVE CARE PERSPECTIVE

- Empathy: The ability to understand the feelings of another

PALLIATIVE CARE

- Care given to improve the quality of life of patients who have a serious, chronic or life-threatening disease.
- The goal of palliative care is to prevent or treat as early as possible the symptoms of a disease, side effects caused by treatment of a disease, and psychological, social, and spiritual problems related to a disease or its treatment.
- In short, symptom management, regardless of where the patient is in the disease process utilizing a biopsychosocial approach

DIFFERENTIATION

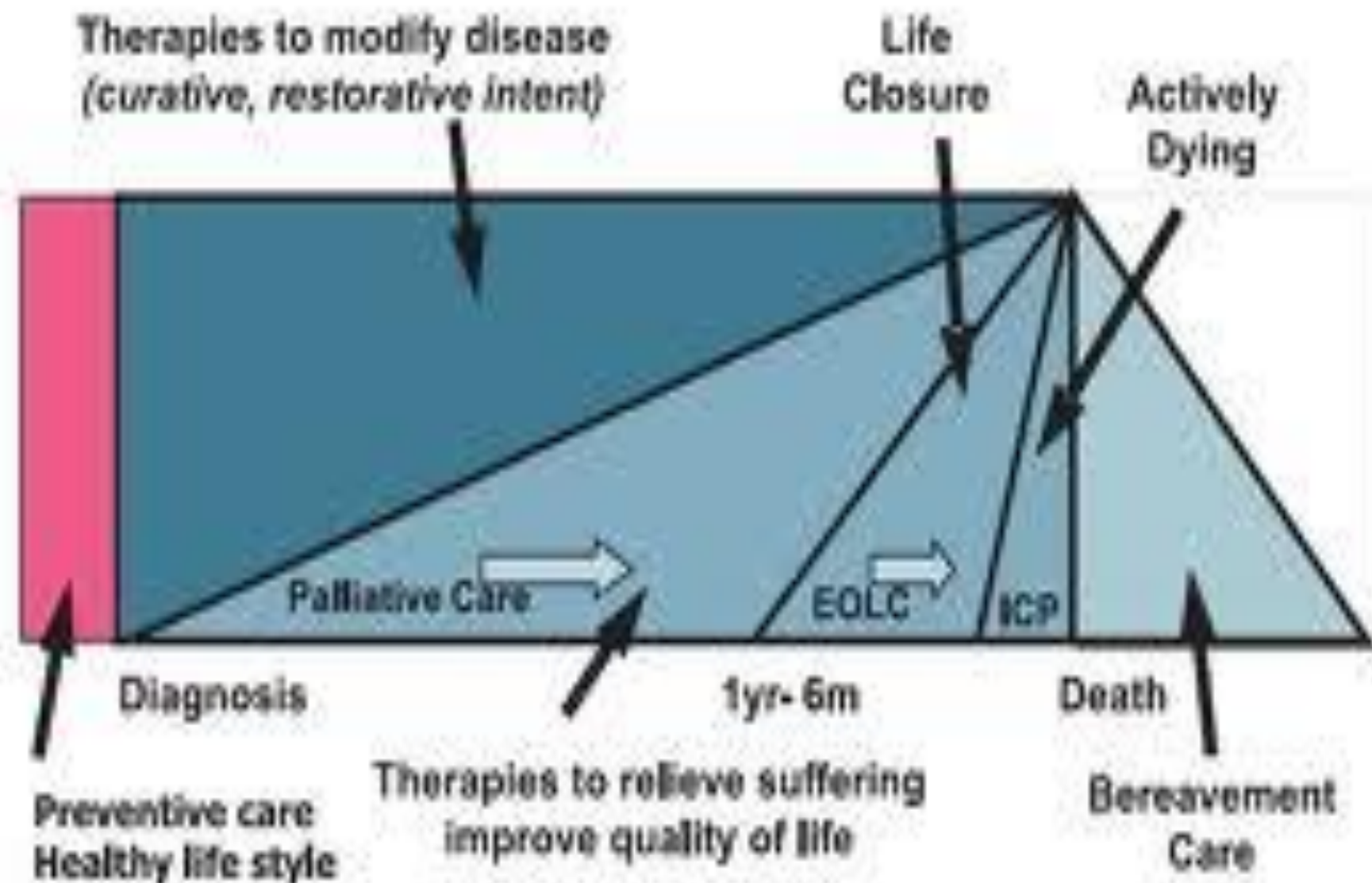
- Hospice: If the disease follows the expected course, a prognosis of six months or less (patients often referred late)
- Palliative: Symptom focused care anywhere throughout the disease spectrum, can be delivered in conjunction with curative care

Why Palliative Care?

- Aggressive measures for control of pain and other distressing symptoms
- Better quality and often longer life, with neither quality or quantity achieved at the other's expense
- More goal centered
- Interdisciplinary team of caregivers, participating in holistic care of patient and family

Modified from-

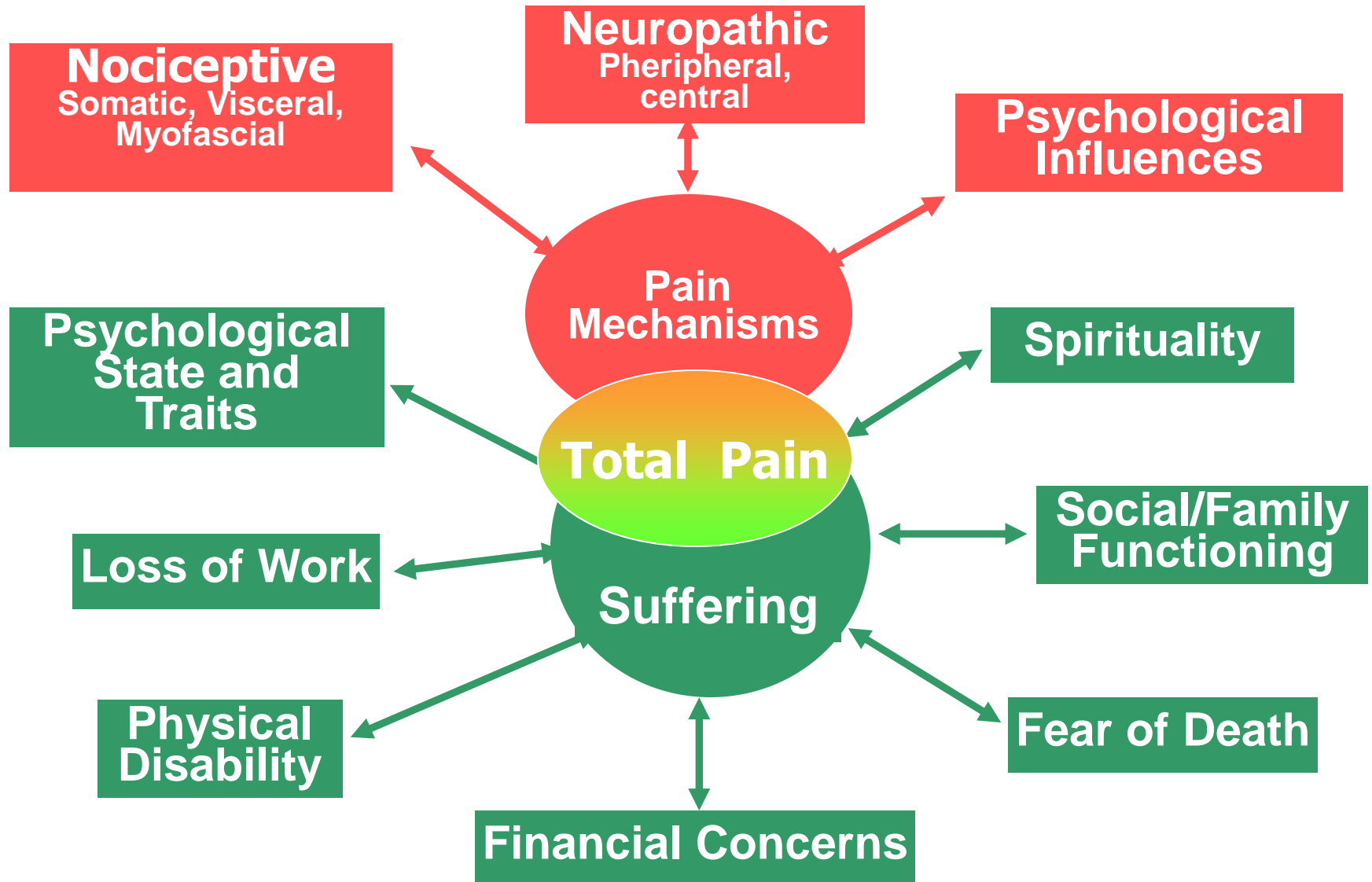
<http://depts.washington.edu/pallcare/training/ppt.shtml>



BASIC CONCEPTS IN PALLIATIVE CARE - PAIN MGMT

- Pain: An unpleasant sensation that can range from mild, localized discomfort to agony. Pain has both physical and emotional components

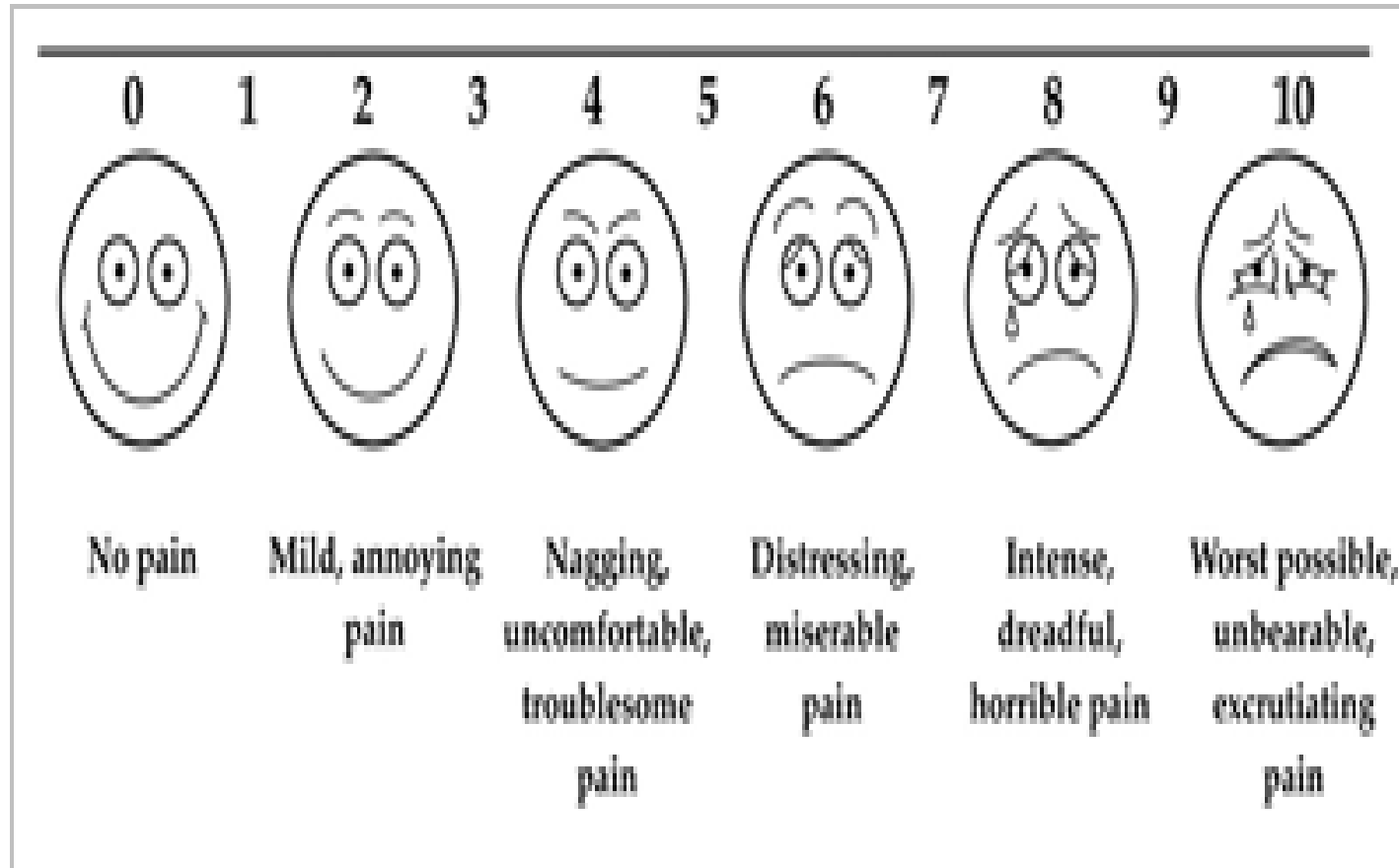
Nature of Pain



ASSESSMENT

- Vital role of nursing in pain and symptom management
- Under appreciated resource
- Goal of assessment and appropriate pain management is to restore functionality

VAS w/WONG-BAKER



PAIN ASSESSMENT (NON-VERBAL)

- CNVI/CNPI Pain Scale w/Move At rest
- Nonverbal vocalizations: * :*
- Facial grimaces/winces :* :*
- Bracing :* :*
- Restlessness :* :*
- Rubbing :* :*
- Vocal complaints :* :*
- Pain score (0-12)=

FUNCTIONAL PAIN SCALE

- Functional Pain Scale-adapted from Gloth et al
- 0 No Pain
- 2 Tolerable (Doesn't interfere with activities)
- 4 Tolerable (Interferes with some activities)
- 6 Intolerable (Able to use phone, TV, or read)
- 8 Intolerable (Unable to use phone, TV, or read)
- 10 Intolerable (Unable to verbally communicate)

**Edmonton Symptom Assessment System:
(revised version) (ESAS-R)**

Please circle the number that best describes how you feel NOW:

No Pain	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Pain
No Tiredness <i>(Tiredness = lack of energy)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Tiredness
No Drowsiness <i>(Drowsiness = feeling sleepy)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Drowsiness
No Nausea	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Nausea
No Lack of Appetite	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Lack of Appetite
No Shortness of Breath	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Shortness of Breath
No Depression <i>(Depression = feeling sad)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Depression
No Anxiety <i>(Anxiety = feeling nervous)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Anxiety
Best Wellbeing <i>(Wellbeing = how you feel overall)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Wellbeing
No _____ Other Problem <i>(for example constipation)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible _____

Patient's Name _____

Date _____ Time _____

Completed by (check one):

- Patient
 Family caregiver
 Health care professional caregiver
 Caregiver-assisted

BODY DIAGRAM ON REVERSE SIDE

Modified WHO Analgesic Ladder

Proposed 4th Step

The WHO Ladder



POLYPHARMACY NIGHTMARE

Avoid the 31 Flavors of Baskin Robbins approach ***for all symptoms:***

- *Stick to the basics.* The basic principle is to titrate one agent to effectiveness or side effect, before introducing a second agent. Use 1 long acting and 1 short acting opiate.
- *Explore the possibilities:* Investigate etiology of pain. Consider complementary approaches. Use opioid sparing adjuvants.

CONCEPT

- DOME
- Daily Oral Morphine Equivalence
- Codeine and meperidine should be avoided

Opioid Prescribing and Equianalgesic

Generic (Brand)	Onset (O) and Duration (D)		Approximate Equianalgesic Dose	
	Oral	IV	Oral	IV
Morphine (MSIR®) [CII]	O: 30-60 min D: 3-6 h	O: 5-10 min D: 3-6 h	30 mg	10 mg
Morphine extended release (MS Contin®) [CII]	O: 30-90 min D: 8-12 h	—	30 mg	10 mg
Hydromorphone (Dilaudid®) [CII]	O: 15-30 min D: 4-6 h	O: 15 min D: 4-6 h	7.5 mg	1.5 mg
Hydrocodone/APAP 325 mg (Norco 5, 7.5, 10®) [CII] Hycet (7.5 mg/325 mg per 15 mL)	O: 30-60 min D: 4-6 h	—	30 mg	—
Fentanyl [CII] (Sublimaze® Duragesic®) <i>Patch for opioid tolerant patients ONLY</i>	Transdermal O: 12-24 h D: 72 h per patch	O: immediate D: 30-60 min	—	100 mcg (0.1 mg)
Methadone (Dolophine®) [CII] <i>Opioid tolerant patients ONLY</i>	O: 30-60 min D: >8 h (chronic use)	—	Variable	Variable
Oxycodone 5, 15, 30 mg (Roxicodone®), Oxycodone 5, 7.5, 10 mg/ APAP 325 mg (Percocet®), ER=Oxycontin® [CII]	O: 10-15 min D: 4-6 h	—	20-30 mg	—
Tramadol (Ultram®) [CIV] ^	O: 1 h D: 3-6 h	—	300 mg	—

^ Not recommended in nursing mothers.

Equianalgesic Opioid Dosing

Drug	Equianalgesic Doses (mg)	
	Parenteral	Oral
Morphine	10	30
Buprenorphine	0.3	0.4 (sl)
Codeine	100	300
Fentanyl	0.1	NA
Hydrocodone	NA	30
Hydromorphone	1.5	7.5
Meperidine	100	300
Oxycodone	10*	20
Oxymorphone	1	10

ONSET OF ACTION

- IV opioids: 5-15 minutes
- Oral opioids: 45-60 minutes
- Transmucosal (fentanyl): 20-30 minutes

METHADONE-BENEFITS

Mu agonist, synthetic opioid:

- Has two non-opiate analgesic receptor activities:
 - Prevents MAO reuptake in periaqueductal gray
 - Prevents N-methyl-d-aspartate (NMDA) receptors
- Lacks neuroactive metabolites
- High bioavailability (79 +/-11 hours)
- Long half life (30 +/- 16 hours)
- Highly lipophilic
- Fecal excretion-safe in ESRD
- Very inexpensive

METHADONE

When converting to Methadone:

- Assess the appropriateness of converting in the home
- Educate to side effects and responses
- Process takes 3-5 days to reach full therapeutic effect
- Breakthrough dosing with another opioid is imperative for transition
- Know the assessment findings that indicate overdose or under dosing

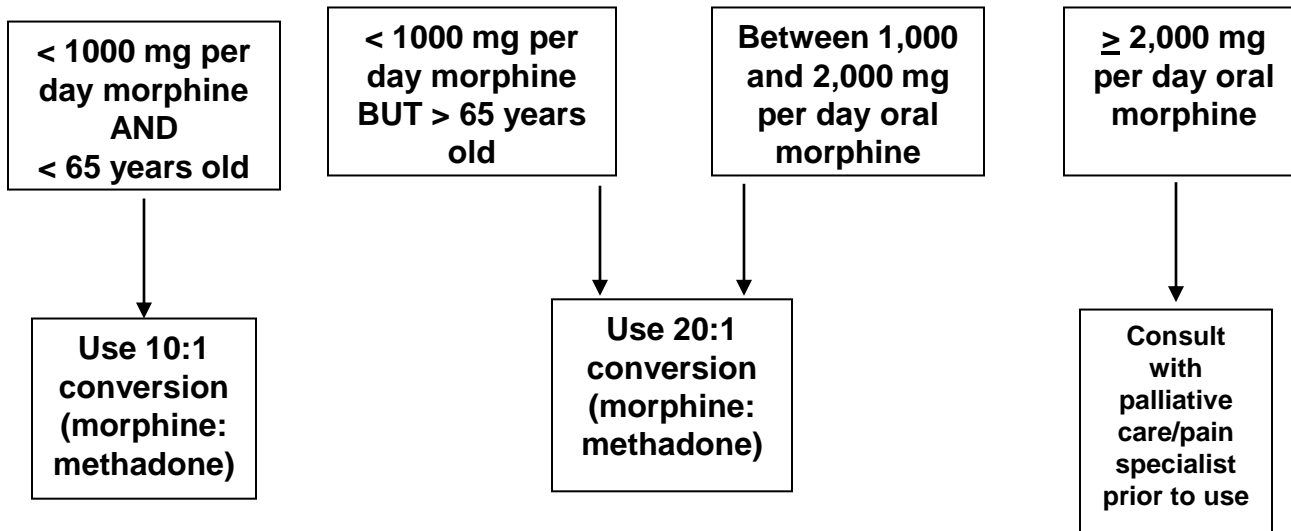
METHADONE PRECAUTIONS

- Lack of caregiver(s) to monitor the patient
- Very limited prognosis
- Increased risk of QT prolongation in patients with known bradycardia or heart failure, patients with hypokalemia or those taking drugs which potentiate QT prolongation.
- Patients with OSA, hypercarbia.

METHADONE DOSES

- Initial dose for opioid naïve patients: 1-2.5mg at bedtime or twice a day
- Use their previous opioid or morphine for breakthrough pain
- With careful oversight, can use methadone for breakthrough(rare) in case of allergies etc..
- IV Methadone is twice as potent as oral

CONVERSION FROM MORPHINE TO METHADONE



FENTANYL PATCH

It isn't for everyone:

- Generally not for beginners. Patient must be opioid tolerant to the minimum equivalent of Morphine 50-65 mg/day, to be able to tolerate 25 mcg of Transdermal Fentanyl . No they can't be cut in half or use prn.
- Need a little fat for the patch. It's a lipophilic agent requiring adequate adipose tissue to facilitate absorption into fatty subcutaneous molecules.
- Not good for a quickie. It takes 12-24 hours for onset of action, not appropriate for acute or emergent pain management.
- Keep it cool. Fever/External heat (102-104°) can increase absorption
- Generally, doubling the strength of the patch will give you the DOME(Daily Oral Morphine Equivalents). For example, a 25 mcg patch will provide approximately **50mg** of oral morphine equivalents per day(please see fentanyl patch manufacturing info/package insert for exact dosing prior to prescribing).

OPIOIDS ARE INCREASED BUT NO PAIN RELIEF IS IN SITE.....

What type of pain is the patient experiencing?

- Somatic, Myofascial, Neuropathic
- Has the pain changed in quality-important in differentiating acute on chronic
- Total body pain
- Emotional suffering/depression-pay attention to pt affect
- Anxiety

PCA PITFALLS

Your patient is getting sleepier and sleepier:

- Is the patient opioid naïve and receiving basal and bolus dosing at the start?
- Is someone other than the patient using the bolus button?
- Is the prescriber increasing the basal rate in response to the patient's persistent complaints of pain?
- PCA to oral
- Does the patient need a long-acting opioid?
- Will prn dosing only provide adequate coverage?
- The pump is off-when should the new regimen start?
- The bolus button becomes a Xbox(Nintendo etc) game(anxiety)*Attempts verses Doses received*
- Continuous opioid infusions even at end of life should only be started once patient has "failed" appropriate titration of ATC parenteral opiates

IMPORTANT DEFINITIONS

- Addiction-characterized by *aberrant behaviors*
- Physical Dependence-need for a substance to function
- Tolerance-requiring increased dose of substance to experience expected effects
- Opioid Naïve-<30mg DOME
- High Dose Opiates->90mg DOME

SABOTAGING SIDE EFFECTS

CNS: drowsiness, confusion, hallucination

- The dose of opioid is excessive
- The pain is not opioid responsive
- Conversion from one opioid to another was done incorrectly
- Other concomitant sedatives being prescribed (most commonly benzos)

Respiratory Depression

- Excessive opioid dose in naïve patient
- Can occur if dosing persists in face of sedation

CASE 1

- 43 YO M WITH 1 YR C/O “DYSPPNEA”(2012-2013)
- NON-SMOKER
- FORMER MILITARY
- LEFT CW PAIN
- MARRIED, 1 ADULT SON W/SPECIAL NEEDS
- ER CT SHOWED LT LUNG MASS
- VATS COMPLETED PATH C/W STAGE 4 NSCLC
- PAIN 8/10 “SHARP,STABBING”
- WHERE DO WE GO FROM HERE

CASE 1 (CONTINUED)

- Gabapentin+IV Ketorolac+IV Hydromorphone Immediate Post-op
- Chemo/RT
- Convert to po dilaudid prn btp prior to d/c, continue and titrate gabapentin, venlafaxine added for depression
- Patient continues to f/u oupt pall care(5yrs later), remains on gabapentin, venlafaxine, “medical marijuana” & crizotinib with good qol

CASE 2

- 72 yo F consulted for acute on chronic LBP
- Initial admit for CHF exacerbation, deconditioning
- Pt with long h/o chronic LBP, s/p spinal cord stim placed at JHU ~5yrs ago
- Given gabapentin at hs and po oxycodone/acetaminophen prn
- Little improvement in pain
- Extremely flat affect

CASE 2 (CONTINUED)

- Pt queried wrt depression
- Dgtr died earlier this month from CA
- Son died almost exactly 1 yr previously from AMI
- Pt w/insight into somatization of depressive features/normal grief process
- Declined additional anti-depressant tx
- Opted to embrace current coping skills (religion, denial)
- Dx-Unresolved/complicated grief

CASE 3

- 52 yo m physician w/widely metastatic prostate ca
- Chemo 1 wk PTA
- Severe pain,dyspnea
- Seen on bipap in ICU,teenage son at bedside
- Taking Oxycontin 80mg po q6h atc with Oxy IR 30mg po q4h prn for BTP

CASE 3 (CONTINUED)

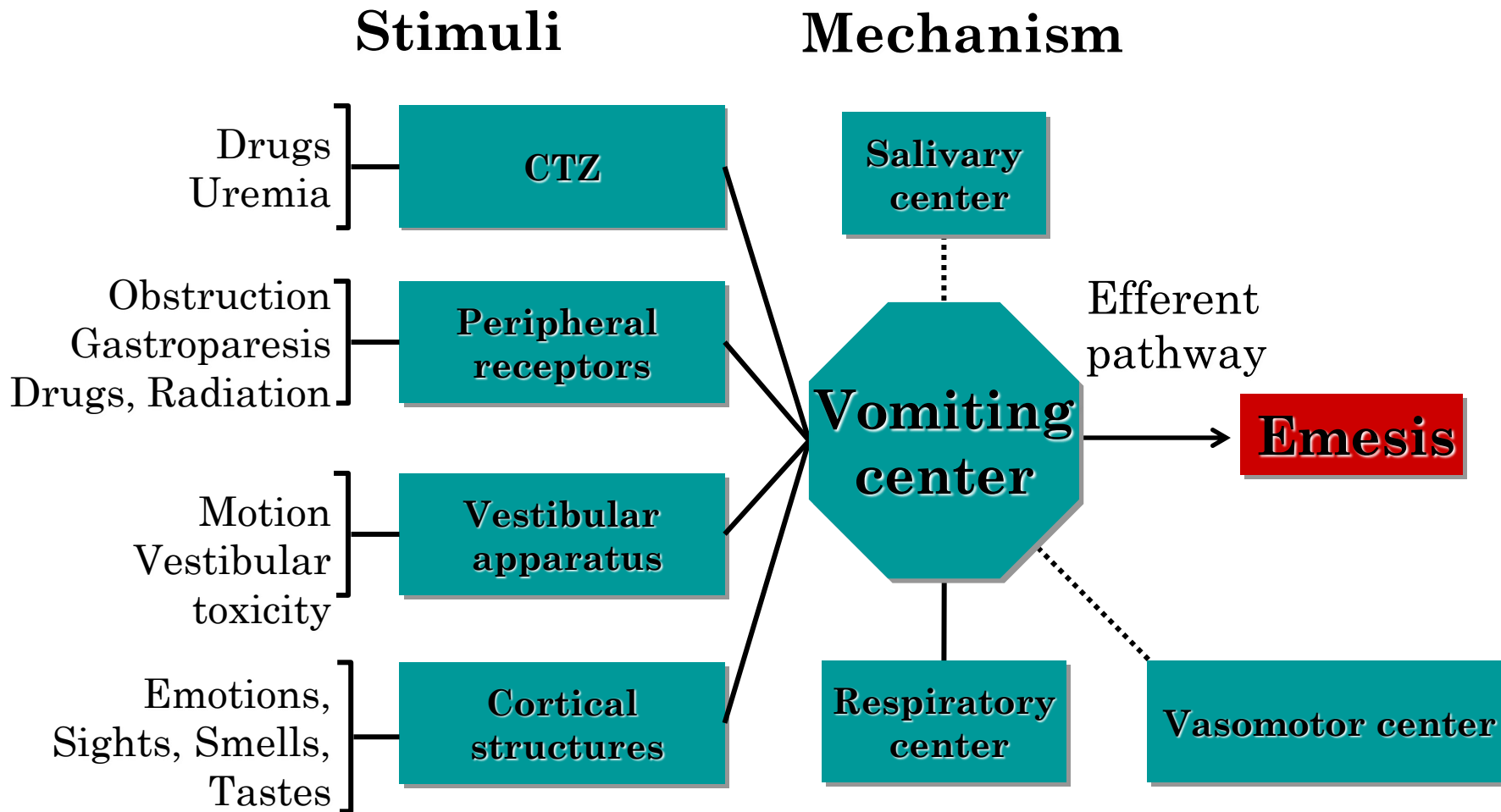
“Physician know thy self”

- Establish goals of care(“break the ice if needed”)
- Do not take hope away but be realistic
- Discuss risks and benefits(we ALL have them)
- Establish a clear plan and objectives
- Calculate DOME as a starting point(convert to hydromorphone PCA Basal 1mg/hr,bolus 0.5mg q6min)
- Use adjuvants(Dexamethasone 8mg IV BID)
- Know the therapeutic index prior to making changes
- Use adjuvants aggressively when possible

NAUSEA

- Definition-stomach distress with a distaste for food and an urge to vomit

NAUSEA & VOMITING



Tortorice and O'Connell. *Pharmacotherapy*. 1990;10(2):129-145; Andrews. *Br J Anaesth*. 1992;69 (suppl 1):2S-19S; Grahame-Smith. In: *Nausea and Vomiting: Mechanisms and Treatment*. Berlin, Germany: Springer-Verlag; 1986:1-8.

ANTI-EMETIC THERAPY

- CTZ
 - Serotonin antagonists *5-HT3*
 - (Ondansteron, granisetron)
- Peripheral and Cortical
 - Corticosteroid
- Benzodiazepine
 - Lorazepam
 - *S/E sedation*
- Butyrophenone
 - Haloperidol
 - *S/E tardive dyskinesia, arrhythmias, hypotension*
- Dopamine antagonist
 - *D2*
 - Metoclopramide
 - *S/E seizures, tardive dyskinesia*
- Cannabinoid
 - *Blocks VC*
 - Dronabinol /Nabilone
 - *S/E alt sensorium, anxiety, mood disturbance*
- Anti-convulsant
 - *Taste related nausea*
 - Clonazepam
 - *S/E drowsiness, ataxia*
- Anti-histamine
 - Meclizine,scopolamine
 - *S/E tachycardia, dry mouth*

COMPLEMENTARY THERAPIES

- Acupressure bands(“Sea Bands”)
- Acupuncture
- Avoid triggers
- Environment
- Music toning
- Relaxation, imagery, diversion therapy
- Meditation
- Hypnosis
- Psychosocial support

CASE 4

- 38 yo M with Stage III Laryngeal CA
- Recent completion of cisplatin
- Undergoing RT
- Persistent N/V
- Has PEG tube
- No recent BM's
- Where do we go from here?

CASE 4 (CONTINUED)

- Metoclopramide 5mg IV q6h ATC with titration upward to 10mg IV q6h ATC
- Nausea improved, now w/emesis without preceding nausea, scopolamine patch added
- MRI brain ordered-negative for CNS/cerebellar mets
- 2nd scopolamine patch added, & reglan titrated up to 10mg IV q4h ATC with adequate symptom control-subsequent med conversion to liquid via PEG and d/c home

CONSTIPATION

- Constipation is defined as having a bowel movement fewer than three times per week

BACK-UP ON THE GI BELTWAY: CONSTIPATION

- Opioids, anticholinergics, antispasmodics, antidepressants, antipsychotics, antiemetics, aluminum antacids, diuretics, iron, vinca alkaloids
- Hypercalcemia, hypokalemia
- Dehydration, polyuria, fever, vomiting
- Inadequate fluid & fiber intake
- Immobility
- Lack of privacy & bowel training
- Autonomic neuropathy/failure
- Bowel ileus or obstruction
- Spinal cord involvement
- Hemorrhoids, anal fissure, perianal abscess
- Radiation fibrosis
- Intracolonic or pelvic tumor mass

TREATMENT

Step 1: Preventative/Maintenance Regime

Stool softner & stimulant

Docusate Sodium/casanthranol

Docusate Sodium/Sennosides

** *abdominal cramping, colic, diarrhea, nausea, vomiting*

Step 2: If no bowel movement in 48 hrs

Hyperosmotic Agents or Laxatives

Lactulose, Poly-ethylene-glycol, Sorbitol

Milk of magnesia, Bisacodyl

** *abdominal distention, pain, flatulence, electrolyte disorders*

TREATMENT

Step 3A: If no bowel movement in 3-4 days

- *Rapid-acting Laxative*

Note: *Administer only in the presence of active bowel sounds & in the absence of rectal fecal impaction, vomiting, severe abdominal cramping*

- Magnesium citrate, Mineral oil 30-60 ml
- ** *malabsorption of fat soluble vitamins, electrolyte disturbance*

Step 3B: if no bowel movement in 3-4 days *Fecal Impaction*

- Pre-treat with analgesia or mild sedative
- Soften stool with glycerin suppository or oil retention enema
- Manually disimpact stool, while encouraging relaxation deep breathing techniques
- Follow with SSE or tap water enemas until clear
- Offer sitz bath, or apply warm compresses, Tucks pads or local anesthetic ointment

PHARMACOLOGIC TREATMENT

- Prokinetic agent:
 - Metoclopramide 5-10 mg QID
 - Erythromycin 250mg IV BID
- Opioid Antagonist
 - Naloxegol
 - Methylnaltrexone
 - Naloxone
- Opioid rotation to lipophilic agent
 - Fentanyl or Methadone

CASE 5

- 46 yo F with Stage 4 Cervical CA
- Cachexia, declining fxnal status
- On opiates as outpt
- Scant BM x 5 wks PTA
- Abd distention and pain
- How do we proceed?

CASE 5 (CONTINUED)

- D/C prn IV hydromorphone with change to Fentanyl PCA
- Initiate adjuvants for pain(gabapentin)
- Metoclopramide 5mg IV q6h ATC with upward titration to 10mg IV q4h ATC
- GI involved mult enemas given, mult scopes performed to try and resolve impaction
- Surgery on board in case of perforation
- Methylnaltrexone given subcut mult times with some results

DYSPNEA

- The subjective sense of breathlessness or smothering.

BACKGROUND

- Dyspnea is the primary complaint of patients with advanced lung or heart disease.
- 94% of patients with chronic lung disease experience dyspnea in the last year of life.
- In SUPPORT (Study to Understand Patient Preferences and Outcomes of Treatment), “serious dyspnea” was far more common (66%) than “serious pain” (25%).
- These investigators reported that patients with COPD were more likely to die with poor control of dyspnea than patients who had lung cancer.

PRINCIPLES

- The experience of dyspnea includes sensory (how severe is it?) and affective (how unpleasant is it?) components.
- Based on a neurophysiological model, breathlessness is thought to be similar to the perception of pain.
- ACCP Statements based on dyspnea that persists at rest or with minimal activity and is distressful despite optimal therapy of advanced lung or heart disease.

ACCP POSITION

- Patients with advanced lung or heart disease should be asked about the intensity and distress of their breathlessness.
- Pursed-lips breathing, relaxation, oxygen for those with hypoxemia, noninvasive positive pressure ventilation, and oral/parental opioids can provide relief of dyspnea.
- Therapies should be started with the understanding that the patient and clinician will reassess whether the specific treatments are relieving dyspnea without causing adverse effects.
- It is important to communicate about palliative and end-of-life care.

PT PRESENTATION

- Shortness of breath
- Breathlessness
- Smothering feeling
- Suffocation
- Present at rest
- Worsened by activity

DIAGNOSIS

- Self-report is the key to detecting dyspnea & appreciating the severity of dyspnea.
- Blood gas, oxygen saturation, and respiratory rate do not substitute for patient's self assessment and report of dyspnea.

GOAL OF TREATMENT

- Should be to improve the patient's subjective sensation rather than trying to modify any abnormality in blood gases or pulmonary function
- *Primum non nocere* - avoid suctioning and other traumatic interventions when possible, start low doses of medications in naïve individuals and titrate appropriately

PATIENT CASE 6

- 86 yo F with CHF
- UTI subsequent hypotension
- Dyspneic and “anxious”

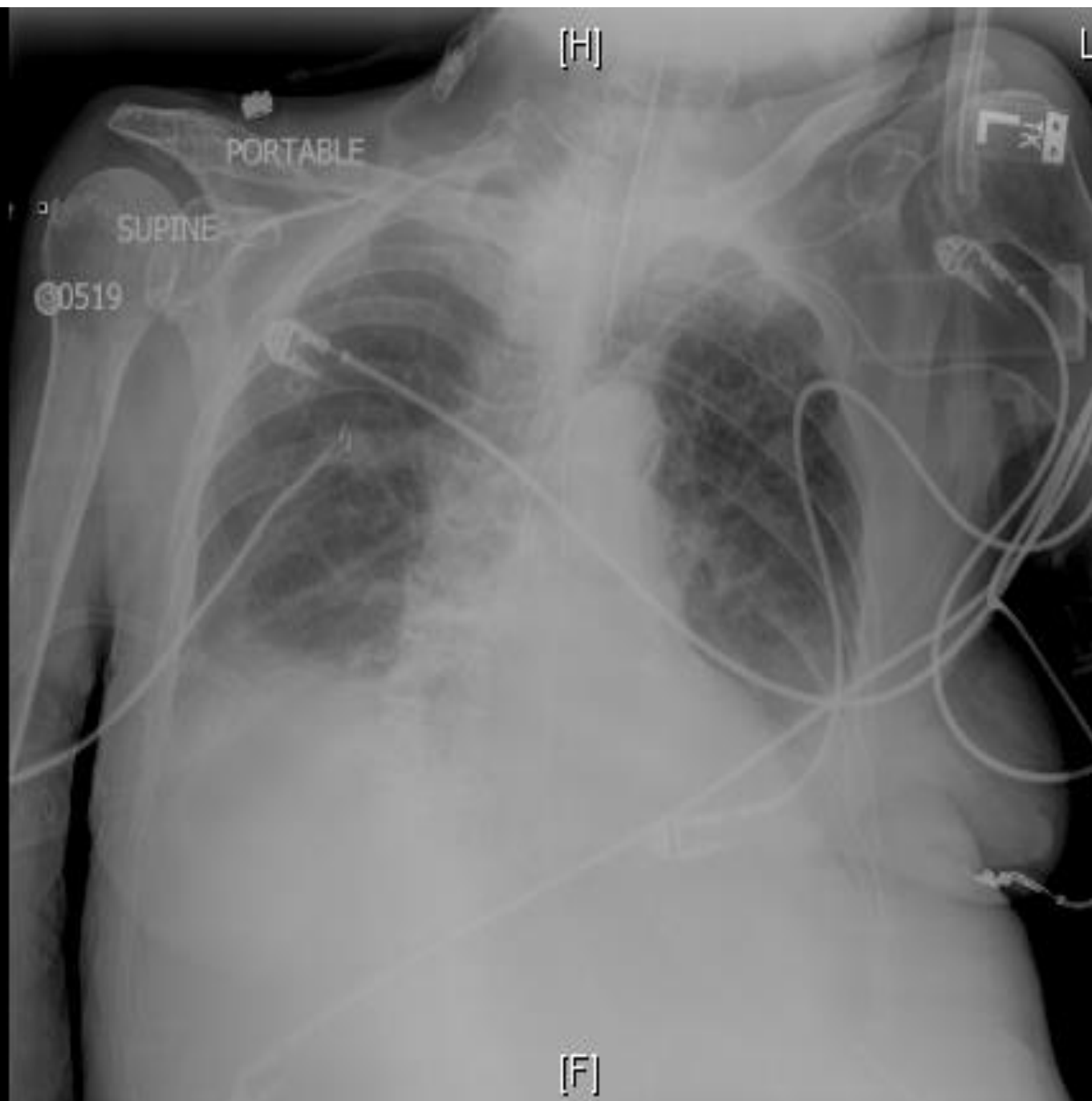
PATIENT CASE 6 (CONTINUED)

- Pt on NRB
- Agitated, dyspneic ,tachypneic, pooling oropharyngeal secretions
- On TPN, with inc wt and dec albumin
- B/L Crackles, poor aeration
- Pt AMS, poor historian, non-verbal cues

Se:1
Im:1

[R]

AP Chest Landscape



TREATMENT

- Address goals of care
- Continue O2 (but remove mask when possible)
- Diurese
- Decrease fluid burden (d/c TPN and IVF)
- Start low dose opiates (ie; Morphine 2mg IV q4h ATC with titration for dyspnea - when goal is comfort, do not hold for parameters such as BP etc)
- Scopolamine patch 1.5 mg top q72 for secretions

AGITATION/ANXIETY IN DEMENTIA

- Agitation/anxiety - a moving back and forth or with an irregular, rapid, or violent action; a feeling of worry, nervousness, or unease, typically about an imminent event or something with an uncertain outcome
- Prevalence 60 to 90 percent of patients
- Both typical and atypical antipsychotics carry **negative mortality benefit (ie increase risk for earlier death)**
- Interventions - remove/treat exacerbating cause if possible (UTI, PNA etc), provide supportive, caring environment, avoid physical restraints, use pharmacologic interventions selectively; if antipsychotics absolutely necessary use low dose preferably via SL route (ie Haloperidol 1mg sl q4h prn)

CASE 7

- 90 yo m with ES dementia (FAST 7A) well cared for at home, acute/chronic
- UTI-TX w/ceftriaxone
- Agitation persists in spite of TX environment
- 24 Hr sitter
- Start Valproic Acid Sprinkels 125mg PO Q6H, ATC w/ improvement in behavior

TAKE HOME POINTS

- *Primum non-nocere (First do no harm)*
- Risk/benefit ratio changes as patients goals of care change
- Palliative care can lengthen lifespan and enhance QOL
- Evaluate the whole patient (look for congruent vs discordant non-verbal cues).
- Maintain your own well-being and appropriate boundaries

KNOWLEDGE CHECK

- Palliative care is the same as Hospice Care T/F
- Morphine is the strongest opiate T/F
- Hydromorphone, Methadone & Buprenorphine are strong opiates T/F
- Dyspnea is defined by Pulse Ox T/F
- Agitation in dementia is best treated with non-pharmacologic interventions
T/F

Pediatrics, Ethics, Spirituality & Grief

Features of Pediatric Palliative

- Epidemiology
- Rare genetic disorders complicate prognosis
- Distinct needs of infant vs child vs adolescent
- Ethical and legal issues
- Impact of terminal illness on family, peers & healthcare providers
- Bereavement implications (often complicated)

1. Papadatou D et al. Education and Training Curriculum for Pediatric Palliative Care. Alexandria, Va.: Children's International project on Palliative/Hospice Services, NHPCO, 2003

10 Leading Causes of Death by Age Group, United States – 2017

Rank	Age Groups									
	<1	1-4	5-9	10-14	15-24	25-34	35-44	45-54	55-64	65+
1	Congenital Anomalies 4,580	Unintentional Injury 1,267	Unintentional Injury 718	Unintentional Injury 860	Unintentional Injury 13,441	Unintentional Injury 25,669	Unintentional Injury 22,828	Malignant Neoplasms 39,266	Malignant Neoplasms 114,810	Heart Disease 519,052
2	Short Gestation 3,749	Congenital Anomalies 424	Malignant Neoplasms 418	Suicide 517	Suicide 6,252	Suicide 7,948	Malignant Neoplasms 10,900	Heart Disease 32,658	Heart Disease 80,102	Malignant Neoplasms 427,896
3	Maternal Pregnancy Comp. 1,432	Malignant Neoplasms 325	Congenital Anomalies 188	Malignant Neoplasms 437	Homicide 4,905	Homicide 5,488	Heart Disease 10,401	Unintentional Injury 24,461	Unintentional Injury 23,408	Chronic Low. Respiratory Disease 136,139
4	SIDS 1,363	Homicide 303	Homicide 154	Congenital Anomalies 191	Malignant Neoplasms 1,374	Heart Disease 3,681	Suicide 7,335	Suicide 8,561	Chronic Low. Respiratory Disease 18,667	Cerebrovascular 125,653
5	Unintentional Injury 1,317	Heart Disease 127	Heart Disease 75	Homicide 178	Heart Disease 913	Malignant Neoplasms 3,616	Homicide 3,351	Liver Disease 8,312	Diabetes Mellitus 14,904	Alzheimer's Disease 120,107
6	Placenta Cord. Membranes 843	Influenza & Pneumonia 104	Influenza & Pneumonia 62	Heart Disease 104	Congenital Anomalies 355	Liver Disease 918	Liver Disease 3,000	Diabetes Mellitus 6,409	Liver Disease 13,737	Diabetes Mellitus 59,020
7	Bacterial Sepsis 592	Cerebrovascular 66	Chronic Low. Respiratory Disease 59	Chronic Low Respiratory Disease 75	Diabetes Mellitus 248	Diabetes Mellitus 823	Diabetes Mellitus 2,118	Cerebrovascular 5,198	Cerebrovascular 12,708	Unintentional Injury 55,951
8	Circulatory System Disease 449	Septicemia 48	Cerebrovascular 41	Cerebrovascular 56	Influenza & Pneumonia 190	Cerebrovascular 593	Cerebrovascular 1,811	Chronic Low. Respiratory Disease 3,975	Suicide 7,982	Influenza & Pneumonia 46,862
9	Respiratory Distress 440	Benign Neoplasms 44	Septicemia 33	Influenza & Pneumonia 51	Chronic Low. Respiratory Disease 188	HIV 513	Septicemia 854	Septicemia 2,441	Septicemia 5,838	Nephritis 41,670
10	Neonatal Hemorrhage 379	Perinatal Period 42	Benign Neoplasms 31	Benign Neoplasms 31	Complicated Pregnancy 168	Complicated Pregnancy 512	HIV 831	Homicide 2,275	Nephritis 5,671	Parkinson's Disease 31,177

Definitions

- Neonate: Birth to 28 days old
- Infant: Birth to 1 year old
- Child: 1-18 years old

Statistics

- About 50,000 deaths annually (~2% all US deaths)
- Children represent 25% US population
- Half of childhood deaths are in first year of life
- Half of infant deaths are in the first month of life

Symptoms in Dying Children

- Most common reported symptoms:
 - Pain
 - Fatigue
 - Dyspnea

Concurrent Care

The “Concurrent Care for Children” Requirement (CCCR) of the Patient Protection and Affordable Care Act stipulates that a child who is eligible for and receives hospice care may concurrently receive all other services that are related to the treatment of the child’s condition. That means that, in addition to curative measures, a child’s care may also focus on enhancing the quality of life, minimizing suffering, optimizing function and providing opportunities for personal and spiritual growth. As that realization has taken root, the healthcare culture and referral sources, as well as patients and their families, are beginning to embrace a dual approach to caring for terminally ill children.

Causes of Deaths All Infants

1. Congenital malformations
2. Short gestation / LBW
3. Sudden Infant Death Syndrome
4. Maternal complications
5. Complications of placenta, cord, or membranes
6. Accidents/unintentional injury

Causes of Deaths

Infants with Complex Chronic Conditions

1. Cardiovascular
2. Congenital / genetic
3. Respiratory
4. Neuromuscular

Causes of Death Children 1-19

1. Accidents
2. Assault
3. Malignancy
4. Suicide
5. Congenital malformations, deformations
6. Chromosomal anomalies
7. Heart disease
8. Cerebrovascular diseases

Causes of Death

Children 1-19 with Complex Chronic Condition

1. Malignancy
2. Neuromuscular
3. Cardiovascular

Diagnoses in Pediatric Palliative Care

- Genetic/Congenital
- Neuromuscular
- Oncologic
- Respiratory
- Gastrointestinal
- Cardiovascular

Some children with multiple diagnoses

Advanced Care Planning

- Children should participate to the fullest extent possible, based on experience of illness, developmental capacities, and level of consciousness.
- Regardless of the prognosis, respect for the child requires that he or she be given a developmentally appropriate description of the condition along with the expected burdens and benefits of available management options, while soliciting and listening to the child's preferences.

Identifying presence of pain

Behaviors seen in validated pain assessment tools for nonverbal children with neurologic impairment

- Vocalizations (crying, moaning)
- Facial expression (grimacing, fussy)
- Consolability
- Interactivity (withdrawn, less active)
- Movement (pulls legs up)
- Tone and posture (arching, stiffening)
- Physiological responses (sweating)

FLACC scale

Behavioral Observation Pain Rating Scale

Categories	Scoring		
	0	1	2
Face	No particular expression or smile; disinterested	Occasional grimace or frown, withdrawn	Frequent to constant frown, clenched jaw, quivering chin
Legs	No position or relaxed	Uneasy, restless, tense	Kicking, or legs drawn up
Activity	Lying quietly, normal position, moves easily	Squirming, shifting back and forth, tense	Arched, rigid, or jerking
Cry	No crying (awake or asleep)	Moans or whimpers, occasional complaint	Crying steadily, screams or sobs, frequent complaints
Consolability	Content, relaxed	Reassured by occasional touching, hugging, or talking to; Distractable	Difficult to console or comfort

Each of the five categories (F) Face; (L) Legs; (A) Activity; (C) Cry; (C) Consolability is scored from 0-2, which results in a total score between 0 and 10.

Faces Pain Scale The scale shows a close linear relationship with visual analog pain scales across the age range of 4-16 years.

Wong-Baker FACES® Pain Rating Scale



0

No
Hurt



2

Hurts
Little Bit



4

Hurts
Little More



6

Hurts
Even More



8

Hurts
Whole Lot



10

Hurts
Worst

CRIES assesses crying, oxygenation, vital signs, facial expression, and sleeplessness. It is often used for infants six months old and younger and is widely used in the neonatal intensive care setting

DATE/TIME						
<p>Crying - Characteristic cry of pain is high pitched. 0 – No cry or cry that is not high-pitched 1 - Cry high pitched but baby is easily consolable 2 - Cry high pitched but baby is inconsolable</p>						
<p>Requires O₂ for SaO₂ < 95% - Babies experiencing pain manifest decreased oxygenation. Consider other causes of hypoxemia, e.g., oversedation, atelectasis, pneumothorax) 0 – No oxygen required 1 – < 30% oxygen required 2 – > 30% oxygen required</p>						
<p>Increased vital signs (BP* and HR*) - Take BP last as this may awaken child making other assessments difficult 0 – Both HR and BP unchanged or less than baseline 1 – HR or BP increased but increase in < 20% of baseline 2 – HR or BP is increased > 20% over baseline.</p>						
<p>Expression - The facial expression most often associated with pain is a grimace. A grimace may be characterized by brow lowering, eyes squeezed shut, deepening naso-labial furrow, or open lips and mouth. 0 – No grimace present 1 – Grimace alone is present 2 – Grimace and non-cry vocalization grunt is present</p>						
<p>Sleepless - Scored based upon the infant's state during the hour preceding this recorded score. 0 – Child has been continuously asleep 1 – Child has awakened at frequent intervals 2 – Child has been awake constantly</p>						

Opioid dosing basics

- Dosage initially based on weight
- Same escalation principles as in adults
- No upper dose limits
- Taste can be a limiting factor (chocolate syrup hides flavor-generally safe for drug)

Morphine

- Gold standard for moderate or severe pain
- Increased half-life and diminished clearance in neonates.
- Starting doses for infants ~50% of older children.
- Infants more sensitive to respiratory depression.

Conditions Appropriate for Palliative Care

- Conditions for which curative treatment is possible but may fail (Cancer)
- Conditions requiring long-term treatment aimed at maintaining the quality of life (Cystic Fibrosis)
- Progressive conditions in which treatment is exclusively palliative after diagnosis (Trisomy 13)
- Conditions involving severe, non-progressive disability (Hypoxic Brain Injury)

Barriers

- Psychological
- Religious
- Fragmented Health Care System
- Financial & Regulatory
- Ethical & Legal
- Research
- Educational

Research

- Limited
- Systematic data are often not available
- Results in decision making about the care of children with little guidance regarding potential burdens versus benefit of medical interventions

Field MF, Behrman R, eds. When Children Die. Washington, D.C.: National Academies Press, 2003

AAP Recommendations

Residency, fellowships, and continuing education Programs should include topics on:

- Palliative Medicine
- Communication Skills
- Grief and Loss
- Managing prognostic uncertainty
- Spiritual Care
- Decision to forgo life sustaining medical treatment
- Alternative medicine

Ethics

- Autonomy
- Beneficence
- Non-maleficence
- Justice
- Quality of life (like beauty, in the eye of the beholder)
- All the above based on principle of respect

Ethical Issues Arise Due to

- Clinical decisions
- Technology
- Decision maker viewpoints/perspectives/differences
- Transference/countertransference
- Lack of planning (ie no advanced directives in acutely ill pt, pt w/out capacity)

Ethical Challenges

- Informed consent
- “Futile treatments” & medicolegal implications(regional variation)
- Nutrition & end-of-life care
- “Suffering”
- Assessing capacity for decision making
- Laws of surrogacy
- Advanced Directives
- Secondary gain issues
- Need for guardianship
- Advancing medical technology vs what would the patient want?
- Religious and cultural context/implications

Autonomy

Individual's right and ability to decide for him - or - herself according to their beliefs, values and life plan

Beneficence

- Doing good on behalf of the patient
- Interpretational differences, whose good?

Non-maleficence

- Primum non-nocere (first do no harm)
- Risk vs benefit vs pt trajectory of illness, wishes & family desires/understanding of disease process

Justice

- Concept of fairness or what is deserved
- Describes what individuals are legitimately entitled to and what they can claim
- Sometimes justice may serve to limit autonomy; what the individual wishes, chooses, or feels entitled to may not be possible or allowable in the context of the society

Spirituality

Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.

Christina Puchalski, M.D., M.S., F.A.P.C., et. al. Improving the Quality of Spiritual Care as Dimension of Palliative Care: The Report of the Consensus Conference. *Journal Of Palliative Medicine. Volume 12, Number 10, 2009.*

Spirituality refers to the propensity to make meaning through a sense of relatedness to dimensions that transcend the self in such a way that empowers and does not devalue the individual.

Reed, P.G. (1992) An emerging paradigm for the investigation of spirituality in nursing. *Research in Nursing & Health, 15(5), 349-357.*

Religion

Religion has specific behavioral, social, doctrinal and denominational characteristics because it involves a system of worship and doctrine that is shared within a group.

Multidimensional Measurement of Religiousness / Spirituality for use in Health Research: A Report the Fetzer Institute / National Institute on Aging Working Group. Kalamazoo, MI: Fetzer Institute 2003 (1999).

Spiritual Traits

- Meaning
- Value
- Transcendence
- Connecting
- Becoming

Sanders, C. Challenges for spiritual care-giving in the millennium. *Contemporary Nurse* 2002 April; 12(2): 107-11

Spiritual Care

Interventions, individual or communal, that facilitate the ability to express the integration of the body, mind, and spirit to achieve wholeness, health, and a sense of connection to self, others, and[/or] a higher power.

American Nurses Association, & Health Ministries Association. (2005). Faith and community nursing: Scope and standards of practice. Silver Spring, MD: American Nurses Association.

Screening Tool

- F-Faith
- I-Importance
- C-Community
- A-Address (Need to address)

Spiritual Distress

“Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis.”

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Common Causes of Spiritual Distress

- Grief
- Concerns about death and afterlife
- Conflicted or challenged belief systems
- Loss of faith
- Concerns with meaning/purpose of life
- Concerns about relationship with deity
- Isolation from religious community
- Guilt
- Hopelessness
- Conflict between religious beliefs and recommended treatments
- Ritual Needs

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Addressing Spiritual/Religious Needs & Outcomes

- Improved pt/family coping, comprehension of illness and disease trajectory
- Improved care planning
- Improved clinical outcomes
- Provision of care that is holistic and patient-centered

Grief

- Grief is the response to any loss and is therefore a common human experience.
- Terminal illness or chronic illness may be replete with losses and grief.
- Losing your own life is associated with grief (self-anticipatory).
- Losing a loved-one is also associated with grief
- Grief may start at the time of diagnosis
- Good end-of-life care has incorporated the concept of good grief (*i.e. a healthy expression of our life force*)

Important Definitions/Delineation

- Grief-psychological, social & somatic reactions to the perception of loss.
- Mourning-cultural response to grief.
- Bereavement-state of having suffered a loss.
- Grief work-grief response requiring the expenditure of physical and emotional energy.

Coping/Grief Response/Bereavement Pearls

- Highly individual
- Supports beneficial (family, community, faith based)
- Many hospice programs offer bereavement services (individual/group)
- Role of faith/spirituality
- Complicated w/loss of a child
- Transference/countertransference
- Substance abuse, mental health issues & prior losses often make more complex
- Many elderly patients/spouses with long marriages may make more complex

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APPENDIX

ONSET OF ACTION - PG 28: NOTES

- The 1992 Agency for Health Care Policy and Research CPG states that pain should be reassessed:
 1. Within 30 minutes of parenteral drug administration
 2. Within one hour of oral drug administration
 3. With each report of new or changed pain
- However, these recommendations pertain to the reassessment of acute pain in an acute care setting.
- Multiple factors determine the appropriate frequency of pain reassessment, including characteristics of the pain (eg duration, severity), patient factors and needs, the clinical setting, and pain management plan (ie type of drug or intervention).
- In the outpatient setting, patients should be instructed to report any changes in pain characteristics, side effects of treatment, and treatment outcomes. Periodic reassessment is recommended in patients with chronic pain to evaluate improvement, deterioration, or treatment-related complications.

NAUSEA & VOMITING – PG 46: NOTES

- The vomiting center coordinates emesis. It is located in the lateral reticular formation of the medulla, adjacent to the structures involved in the coordination of vomiting (cranial nerves VIII and X and the vasomotor, respiratory, and salivary centers).
- Vomiting results from the stimulation of a multistep reflex pathway controlled by the brain. It occurs when efferent impulses are sent from the vomiting center to the salivation center, abdominal muscles, respiratory center, and cranial nerves.
- There are many stimuli that can contribute to poorly controlled emesis in patients receiving complex, multiday chemotherapy.
- Some of these stimuli, such as motion, uremia, smells, or tastes, act centrally in the brain to stimulate the vomiting center.
- Others, such as gastroparesis and radiation, primarily interact peripherally by stimulating afferent impulses from the gut to the vomiting center.
- Chemotherapy drugs stimulate emesis both centrally and peripherally.

ANTI-EMETIC THERAPY – PG 47: NOTES

- Corticosteroids are widely used to control CINV; their antiemetic mechanism of action is unknown, but it may be mediated through inhibition of prostaglandin synthesis.
- At equivalent doses, corticosteroids have equivalent safety and efficacy and can be used interchangeably. The corticosteroids most commonly studied for use as antiemetics have been dexamethasone and methylprednisolone. Dexamethasone has the advantage of being available in many dosage formulations.
- For acute CINV, corticosteroids (eg, dexamethasone, methylprednisolone) add approximately 20% to 25% to the emetic response rates of cancer patients when given with a serotonin antagonist, compared with using the serotonin antagonist alone. For delayed CINV, dexamethasone and serotonin antagonists appear to have equivalent antiemetic activity.
- Use of corticosteroids in hematologic malignancy patients may be prohibited by treatment protocols either because of theoretical concerns about drug interactions or infection concerns in high-risk patients.
- Often the cancer treatment regimen already includes a corticosteroid, the administration of which should be scheduled close to chemotherapy administration to take advantage of the synergy with serotonin antagonists.

Statistics – Pg 77: Notes

- 0.06% children die

Causes of Death Children 1-19 with Complex Chronic Condition – Pg 83: Notes

- Looking at the pediatric population as a whole, total
- Preventable deaths (accidents/unintentional injuries, assault/homicide) account for 27% of deaths

Focus Outline- MANAGEMENT OF NON-PAIN CONDITIONS & GRIEF

- Management bladder spasms
- US Overall Mortality Data and by Age Group
- Risk/benefit of stimulants
- Bereavement
- Grief
- ESRD and HD risk/benefit
- Neuropathy diagnosis and management

POSTTEST/QUIZ

Please click on the link below to be taken to this activity's quiz. After successful completion, you can then fill out an evaluation and application for CME credit.

[Management of Non-Pain Conditions and Grief](#)