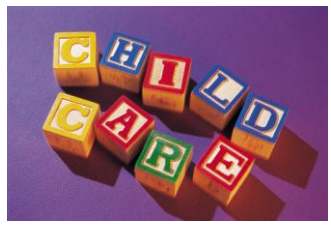

Symptom Management in Pediatric Palliative Care

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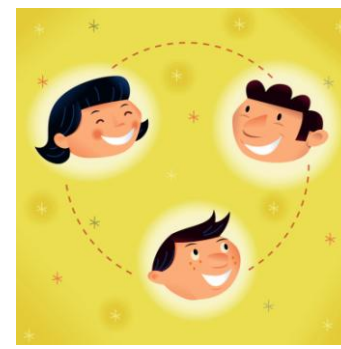
MJHS Hospice and Palliative Care

General Principles



- Individualized patient care
- Interdisciplinary team
- Effective communication
- Improvement of quality of life
- Including the patient and family in the discussion about the plan of care

Head, Neck, Eyes, Ears and Throat

- Oral thrush – fungal infection on the mucous membranes of the mouth
  - Altered immune system
  - Other diseases
  - Medications
  - Poor oral hygiene
    - Assessment
      - Dysphagia
      - Inspection of oral mucosa
      - Assess quality of voice, speech and swallowing

- Treatment
  - Topical therapy
  - Nystatin
    - Neonates – 100,000 units (1ml) QID or 50,000 units to each side of mouth QID
    - Infants – 200,000 units (2ml) QID of 100,000 units to each of mouth QID
    - Children/adults – 400,000 - 1,000,000 (4-10ml) QID

    - If there is no improvement within 48 hours, consider treatment with fluconazole
    - Children with HIV/AIDS it has been shown a decrease in oral thrush 2/2 the use of antiretrovirals and the protease inhibitors

Mucositis

- Radiation
- Chemotherapy
  - Assessment - inspect the entire oral cavity for ulcerations, erythema or fissures
  - WHO classification of Oral Mucositis
    - Grade I – soreness, erythema
    - Grade II – erythema, ulcers, able to eat solids
    - Grade III – confluent ulcers, liquid diet only
    - Grade IV – hemorrhage, open lesions, parenteral nutrition only

- Treatment –
  - Good mouth care
  - Sulcrafate (Carafate) – swish and swallow
  - "Magic mouthwash" – viscous lidocaine and Maalox, diphenhydramine – swish and spit q 2 hours (Grade I-III)
  - Aggressive pain management – may include morphine, dilaudid or fentanyl IV for Grade III or IV

- Prevention –
  - Meticulous mouth care before , after and during the course of chemotherapy and radiation
  - Use of a soft bristle toothbrush
  - Floss teeth regularly
  - Swish and spit non-alcohol mouthwash
    - For children younger than 3 years of age, use a soft cloth or cotton swab to gums and teeth

Xerostomia

- Radiation therapy
- Medications – antihistamines, anticholinergics
- Dehydration that is related to the withdrawal or limitation of artificial hydration
- BiPAP or CPAP
- Mouth breathing
  - Observe the entire oral cavity
    - Treatments
      - Cool air humidification
      - Swabs to moisten oral mucosa
      - Ice chips or sucking candy to stimulate salivation
      - Moisten lips
      - Provide fluids if appropriate

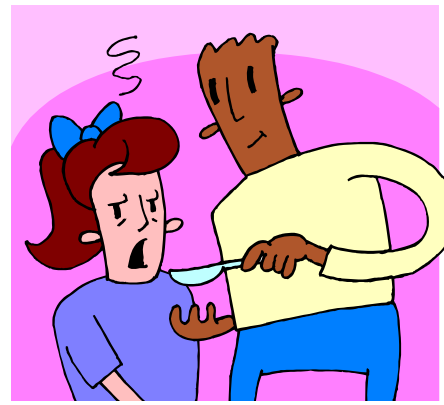
- Prevention
  - Provide cool mist or fan at the bedside
  - Humidify the air in the room

Sialorrhea

- Inability to swallow – secretions collecting in the posterior pharynx. Sometimes referred to as "noisy respirations".
- Assess the color and character of the secretions
  - Treatments are provided based on how patient tolerates
    - Sometimes less treatment is better
    - Suction as needed, avoid deep suctioning, possibility of causing abrasions or bleeding. Use bulb syringe for younger children
    - Scopolamine TDP q 72 hours
    - Robinul (Glycopyrrolate) – less sedating than scopolamine and maybe better for active children
      - Side effects of anticholinergics – dizziness, tachycardia, constipation and dizziness

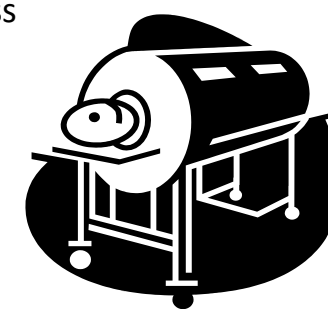
- Prevention
  - Meticulous mouth care
  - Laying the child or infant on their side to minimize pooling of secretions
  - Keeping the head of the bed raised to drain secretions

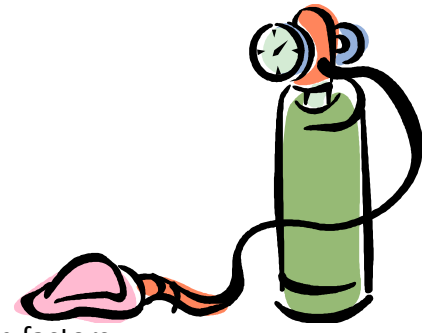
Respiratory



Dyspnea

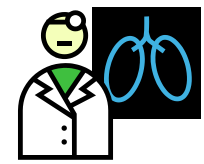
- Malignant/Non-malignant pleural effusion
- Anxiety
- Increase in intracranial pressure
- Respiratory muscle weakness
- Upper airway obstructions
- Thick secretions



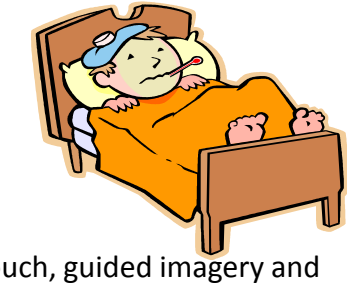


- Assessment
  - Pediatric Dyspnea Scale
  - Precipitating and relieving factors
  - Onset and length of time that the child has been having breathing difficulty
  - Using oxygen
  - What medications have been used to date for symptom management

- Physical exam
  - Use of accessory muscles
  - Auscultation of all lungs fields, listening for adventitious sounds, decrease in air movement
  - Quality and depth of respirations
  - Assessing for stridor, obstructive noises, upper airway congestion

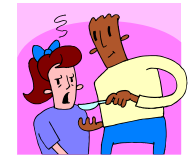


- Treatment
  - Elevate the head of the bed
  - Opioids is helpful to open the airway and provide comfort – Morphine sulfate is used most often. Start low and titrate up with patients who are opioid naïve
  - O2 at high flow, cool air mist or cool air from a fan blowing directly on the child
  - Anxiolytics
    - Benzodiazepines can decrease respiratory drive of children. Hypoxia can exacerbate the feeling of distress and cause additional discomfort
    - Decrease anxiety that is associated with dyspnea
    - Bronchodilators used to improve air exchange in the lungs



- Treatments continued
  - Relaxation such as massage, touch, guided imagery and music therapy
  - Prevention
    - Talking with patient and the family about what precipitated the event
    - Encourage the use of measures taught to minimize exacerbations

Cough



- Asthma
- Bronchiesctasis lung disease (cystic fibrosis, rheumatic disease, previous rounds of radiation)
- Infection
- Allergies
- Aspiration – related to GERD, children with neurological disease have a weak cough
  - Assessment
    - Etiology
    - Quality (wet vs. dry hacking, brassy or barking sound)
    - How long the cough lasts
    - Age
    - Exposure to irritants, allergies or tobacco

- Treatment of a cough is dependent on the underlying cause
  - Asthma – bronchodilators
  - Bronchiectasis – antibiotics, bronchodilators, chest PT, decrease secretions, easing airway obstruction
  - Infection – antibiotics
  - Aspiration – antibiotic therapy, repositioning the child when feeding with the head of the bed elevated and when sleeping, PPI
  - Prevention
    - Awareness of factors that may aggravate or cause cough
    - Careful assessment of the underlying cause
    - Reassurance of the family and patient calmly

Cardiovascular

Edema

- Renal failure
- Fluid overload
- Superior vena cava syndrome
- Liver failure – ascites

- Assessment
  - Complete H&P
  - Labs – BUN, Creatinine, BUN/Cr ratio, LFTs
  - Presentation of SVC – dyspnea, headache, upper body edema, change in mental status
  - Gait coordination

- Assessment continued –
  - Measure extremities
  - Assess texture of skin (color, perfusion, temperature)
  - Pitting vs. non pitting edema
  - Abdominal pain related to ascities in liver disease
  - Dyspnea related to pressure on the diaphragm

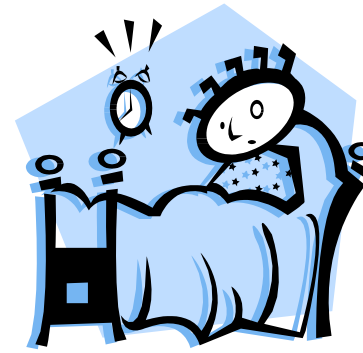
- Treatment –
  - SVC – palliative radiation and corticosteroids, considered an Oncologic emergency
  - Renal failure – dialysis depending on goals of care, diuretics, dietary management
  - Fluid overload – diuretics, massage, elevate extremities, discontinue IV fluids (discuss with family if part of treatment)
  - Liver failure – reduce sodium intake, diuretics, paracentesis, Aldactone

- Prevention –
  - Discuss with patient and family cause of edema, treatment and management options
  - Monitor intake and output
  - Instruction of massage
  - Using compression stockings for children whose mobility is limited

Gastrointestinal

Nausea

- Medication – chemotherapy, opioids, GI stimulants
- Tumor/increase in ICP
- Bowel obstruction
- Constipation
- GI upset – viral or bacterial
- Impaired gastric emptying
- Impaired GI tract motility



- Assessment
  - Stool pattern
  - Diet
  - Medications
  - Emesis pattern
  - Radiation therapy
  - Level of dehydration

- Treatment
  - Medication related – Reglan, Compazine, Dronabinol , rotation of opioids
  - Chemo related – Zofran, steroids, benzodiazepines
  - Gastroenteritis – oral rehydration therapy (infants - Pedialyte, children >2yrs – Gatorade) Administer slowly – give 1-2ml/kg per weight of child q 5 minutes for 3- hours
  - Bowel obstruction
    - Non-Malignant – increase fluid and fiber if appropriate, stool and laxative combination
    - Malignant – Reglan, Scopolamine, Octreotide, Compazine, Haldol, NG tube

  - Dexamethsasone
  - GI illness/virus – supportive care, encourage simple foods and fluids if congruent with the child's palliative goals of care, assessment of intake and output

  - Prevention – adequate nutrition and hydration if appropriate with goals of care
  - Provide antiemetic, MiraLax, stimulant and softener

Diarrhea

- Chemotherapy
- Antibiotics
- Radiation
- HIV/AIDS related infections
- Malabsorption (cystic fibrosis)
- Worsening in malignant disease
- Foods with large amount of sorbitol and fructose
- Change in formula
- Infection

- Assessment
  - Recent change in diet
  - Frequency
  - Character of stool
  - Complaint of pain or cramping
  - Bowel sounds
  - Skin integrity
  - Skin turgor (sign of dehydration)

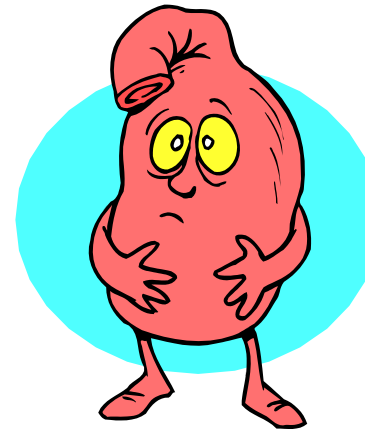
- Treatment
  - Loperamide (only in acute cases and with children under 12 to be used with caution)
  - Anti-cholinergic to reduce gastric secretions
  - Octreotide
  - Assessment of feeding schedule (rate, amount, strength and slowly increase as tolerated)
  - Avoid hyper osmotic supplements
  - Fluid replacement
  - Antibiotics for infections

- Prevention
  - BRAT diet (bran, rice, apples and tea)
  - Dietary interventions
  - Plain foods
  - Increase fluids in diet
  - Low residue diet

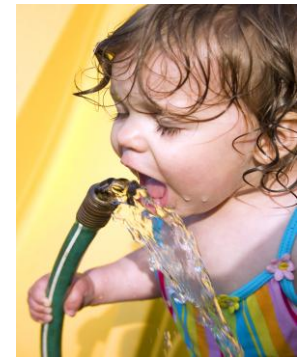
Constipation

- Medication related
- Diet
- Inactivity
- Hypothyroid
- Cerebral palsy
- Cystic fibrosis
- Hemorrhoids/fissure
- Weakness
- Hypercalcemia
- Hypocalcemia
- Uremia
- Neurologic

- Assessment
  - History
  - Pain with bowel movement
  - Character of stool
  - Volume of stool
  - Usual bowel pattern
  - Last bowel movement
  - Inspect abdomen for fullness or distention
  - Auscultate for bowel sounds
  - Palpate for masses or bulges



- Treatment
  - Depends on the cause
  - Consider goals of therapy
  - Analgesia
  - Reduction of gastrointestinal secretions
  - Bowel prep should be initiated when starting opioids for pain management
  - Increase in fluids if appropriate
  - Increase activity if appropriate



- Prevention
  - Bowel regimen for patients on chronic opioid therapy or disease related constipation
  - Provide adequate nutrition and hydration, if congruent with goals of care
  - Encourage activity if appropriate

Genitourinary

Urinary Retention

- Obstruction/tumor growth
- Damage to the nervous system
- Neurogenic bladder – spinal cord lesions
- UTI
- Side effects from medication
- Bladder spasms
- Fecal impaction
- constipation

- Assessment
  - Onset of symptoms
  - What makes it better or worse
  - Recent medical treatments
  - Palpation of bladder
  - Medication history

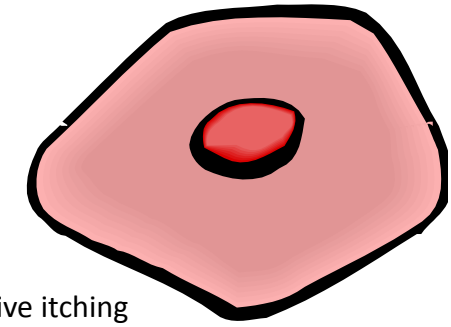
- Treatment
  - Contingent on goals of care, treat the underlying cause and/or discontinue medications contributing to retention
  - Encourage bladder training
  - Intermittent catheterization
  - Bethanechol
  - Oxybutynin
  - Treatment of constipation

- Prevention
  - Teaching signs and symptoms of obstruction/retention
  - Medication side effects
  - Encourage bowel regimen

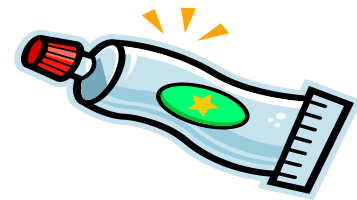
Skin

- Pruritis
  - Medications (opioids, antibiotics)
  - Dry, flaky skin
  - Renal disease (build up of uremia)
  - Contact dermatitis
  - Liver disease (build up of bile salts)
  - Allergies
  - Fungal infections

- Assessment
  - Location
  - Rash
  - Excoriation from excessive itching
  - What makes it worse/better
  - Quality of symptoms
  - Assess integrity of the skin
  - Presence of rash, discoloration (jaundice)



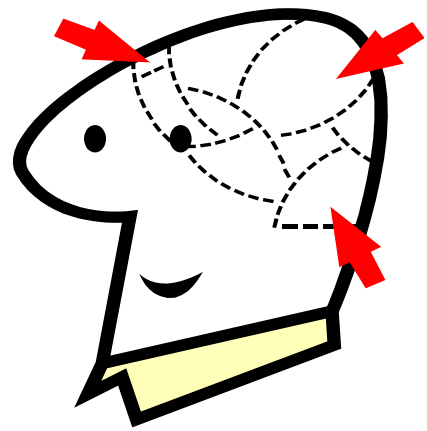
Skin Cell



- Treatment
  - Topical treatment (corticosteroids not more than twice a day and not to be used on the face of young children)
  - Cholestyramine (hepatic disease)
  - Opioid rotation
  - Cholestyramine, zofran (renal disease)
  - Antihistamine
  - Antifungal

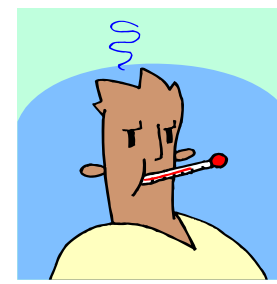
- Prevention
  - Application of moisturizers
  - Loose fitting clothing
  - Change clothing if wet
  - Humidified air in the room

Neurological



- Terminal agitation
  - Infection
  - Hypoxia
  - Disease progression
  - Uncontrolled symptoms
  - Anxiety of caregivers
  - Hepatic or liver disease leading to metabolic insufficiency
  - Autonomic instability

- Assessment
  - Pain
  - Urinary retention
  - Nausea
  - Pruritis
  - Dyspnea
  - Infection/fever
  - Constipation
  - Increased secretions



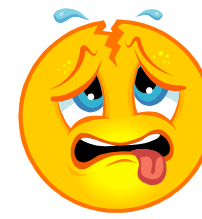
Treatments

- Soft lighting
- Massage
- Music therapy
- Minimize noise
- Aromatherapy
- Acupuncture
- Teach comforting techniques to caregiver

- Ativan – 0.025mg/kg/dose q 6 hr ATC
- Versed – 0.2-0.75mg/kg/dose PO, max dose 20mg
- Haldol – 0.05mg/kg/day BID or TID –titrate to max dose
- 0.15mgkg/day

- Prevention
  - Assessment of the environment
  - Decrease stimulation
  - Provide anticipatory guidance for the family about the course of the disease and possible causes of agitation
  - Treatment of the underlying cause

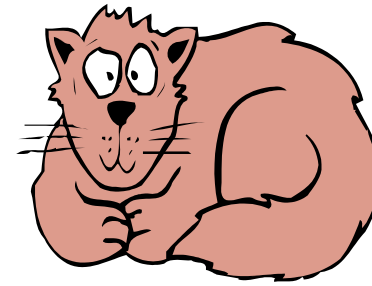
Seizures



- Congenital hydrocephalus
  - Infection, intracranial hemorrhage
  - Excessive CSF fluid in the brain at birth
  - Neurological impairment depends on how much of the brain has been compromised
  - Treatment
    - VP Shunt
    - Treatment started early improves prognosis

- Other neurological diseases that cause seizures;
  - Batten disease
  - Zwellweger syndrome
  - Trisomy 12 (CLL)
  - Trisomy 13
  - Malignancy
  - Metabolic abnormalities
  - Infection (Meningitis, Cytomegalovirus, Encephalitis)

- Assessment
  - Family history of seizures
  - Pattern
  - Duration of seizure
  - Precipitating factors
  - Eye deviation
  - Staring spells
  - Lip smacking or sucking
  - Eyelid fluttering
  - Tonic/clonic movements
  - apnea



- Treatment
  - Phenobarbitol
  - Dilantin
  - Lamictal
  - Keppra
  - Emergency management
    - Diazepam – DiaSTAT, rectal
    - Ativan

Psychological

Anxiety

- Hypoxia from dyspnea
- Constipation
- Urinary retention
- Uncontrolled pain
- Sleep deprivation
- Treatment failure
- Relapse
- Re-hospitalization

- Assessment
  - Physical assessment to rule out physical cause
  - Assess for emotional crisis and spiritual needs
  - Assess for changes in child's personality
  - Developmental changes
    - Toddlers and young children – clingy, irritable, inconsolable, temper tantrums
    - School age children and teens – worry, chronic apprehensive, sleep disturbances/deprivation

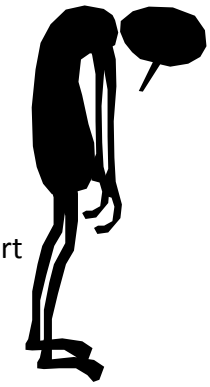
- Treatment
  - Art therapy
  - Music therapy
  - Massage
  - Child life
  - Caring touch
  - Guided imagery (for children > 3 yrs)
  - Aromatherapy
  - hypnosis

- Treatment continued
  - Ativan
  - Haldol – rarely used in children under two years of age. Avoid using in children < 12 years. EKG to be done prior to use. Haldol given IV can cause prolonged QT syndrome

Depression

- Change in disease process
- Family history of depression
- Medications
- Side effects from medications
- Inability to cope with prognosis or diagnosis

- Assessment
  - Sad face, demeanor, irritability, tearful
  - Loss of interest in activities
  - Poor appetite
  - Lack of energy
  - Unable to sleep
  - Changes in relationships
  - Loss of independence
  - Changes in physical appearance



- Assessment continued –
  - Assess for suicidal ideation
  - Change in home setting or change in support
  - Unremitting pain
  - Excessive fatigue
  - Medications that may cause depression
  - Withdrawing from activities with family
  - General complaint “I just don’t feel good”

- Treatment
  - Include social workers and psychologist in discussing plan of care
  - Child life interventions
  - Art therapy
  - Music therapy
  - Massage
  - Play therapy
  - Family therapy
  - SSRI’s – Lexapro, Prozac, Elavil