Hospice 101 Class 3

Home Health Foundation
The Leaders in Home Health and Hospice Care

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Hospice 101 – Class 3

- Medications
- Symptom Management in End of Life Care
- Effective Strategies for Communication with Patients and Families at End of Life

Comfort Kits

- Comfort kits are prescribed by patient's attending physician (preferred) or Medical Director (MD or NP)
- Effective and safe use of comfort kit medications requires a responsible caregiver(s) who understands their use, documents doses given, and calls Hospice with questions and problems
- Needs cautious and full assessment by IDT before prescribing a kit

Comfort Kit Contents

- Acetaminophen 650 mg oral every 4 hours prn fever
- Acetaminophen sup 650 mg rectal every 4 hours prn fever
- Bisacodyl 10 mg rectal once a day prn constipation
- Haloperidol 0.5-1 mg oral every 6 hours prn nausea/vomiting/ agitation

Comfort Kit Contents

- Hyoscyamine tablet 0.125 mg sublingual every 4 hours prn secretions/noisy respirations
- Lorazepam 0.25-1.0 mg oral every 6 hours prn anxiety or agitation
- Roxanol 5-10 mg oral sublingual every 2 hours prn/respiratory distress
- Senna S 1-4 tablets oral Bid prn constipation

Comfort Kits

- May require a family meeting, lockbox and controlled substances contract
- Comfort kit medications and/or dosages are altered by the Hospice team based upon clinical and psychosocial situations, such as:
  - Substance abuse by patient and/or caregivers
  - Severe renal failure. Morphine is contraindicated and hydromorphone should be substituted for short acting relief of pain and dyspnea

Comfort Kits

- Comfort kit medications and/or dosages are altered by the Hospice team based upon clinical and psychosocial situations, such as:
  - Dementia. Majority of comfort kit medications (opioids, anticholinergics, benzodiazepines) can cause serious side effects in patients with all types of dementia. Haloperidol can worsen symptoms in patients with Parkinson's disease and dementia with Lewy bodies and should be eliminated from the kit.

Comfort Kits Procedure

- Comfort Kits are ordered upon admission or during the Hospice stay
- The Admission Nurse will identify the need for the Comfort Kit upon admission and obtain an order from the attending physician
- If the need for a Comfort Kit arises during the Hospice stay, the primary nurse will obtain an order from the attending physician

Comfort Kits Procedure

- If the attending physician is not available to provide a timely order for a Comfort Kit in an urgent situation, an order may be obtained from the Medical Director (MD or NP)
- The availability of a responsible caregiver will be assessed at admission by the Admission Nurse, and throughout the Hospice stay by the primary nurse and other members of the IDT

Comfort Kits Procedure

- Upon admission and throughout the Hospice stay, the IDT will assess patient and caregivers for signs/symptoms of substance abuse/diversion.

- The presence of diagnoses of dementia and severe chronic renal failure will be assessed on admission and throughout the Hospice stay to identify situations where the use of the standard Comfort Kit is contraindicated

Pharmacy Services

- Pharmacy services needed by Hospice patients/families/caregivers and Hospice staff are available 24 hours a day
- Medications are available through contracts between specific pharmacies and Merrimack Valley Hospice

Pharmacy Services Procedure

- The Hospice nurse contacts the patient's attending physician for medication orders
- The attending physician must submit a verbal or written order to the pharmacy for the medication (may be communicated via RN case manager)
- The pharmacy assumes responsibility for safely and accurately preparing, dispensing and delivering the ordered medication

Pharmacy Services Procedure

- The pharmacy delivers the medication to home care patients or notifies the patient/family/caregiver when the medication is available for pick-up or delivery
- The pharmacy dispenses a quantity of medication consistent with the patient's life expectancy as well as appropriate dosage and frequency of the medication as per MD order

Pharmacy Services Procedure

- Education on drug use and adverse effects is provided to the patient by the pharmacy and the RN Case Manager or designee
- Under no circumstances will a nurse leave the patient's home with medications

Symptom Management in End-of-Life Care

- Dyspnea/Breathlessness
- Nausea/Vomiting
- Terminal Agitation
- Syndrome Imminent Death

Dyspnea/Breathlessness

- May be described as shortness of breath, a smothering feeling, inability to get enough air, suffocation
- Assessment
  - What makes your breathlessness worse?
  - What makes it better?
  - How often does it occur? How long does it last?
  - How severe is it?
  - Do you have a cough, fever, chest pain, swelling in your legs or abdomen?
  - Explore life stresses, worries, fears

Physical Exam

- Vital signs
- Appearance - Color, expression, posture, use of accessory muscles, ability to speak
- Heart - rate, rhythm, murmurs, gallops
- Abdomen - size, masses, fluid
- Extremities - edema, perfusion

Physical Exam

- Lung exam:
  - Stridor: upper airway obstruction (trachea)
  - Rhonchi: upper airway obstruction (large bronchi)
  - Wheezes: lower airway obstruction (bronchioles)
  - Crackles: fluid in lower airway (alveoli)
  - Absent breath sounds: pleural effusion, Pneumothorax

Causes of Breathlessness

- Anxiety
- Airway obstruction
- Bronchospasm
- Hypoxemia
- Pleural effusion
- Pneumonia

Causes of Breathlessness

- Pulmonary edema
- Pulmonary embolism
- Thick secretions
- Anemia
- Metabolic
- Family / financial / legal / spiritual / practical issues

Treatment of Dyspnea

- Treat the underlying cause!
- Symptomatic management
- Oxygen
- Opioids
- Bronchodilators
- Anxiolytics
- Nonpharmacological interventions

Oxygen

- Pulse oximetry provides one measure of dyspnea
- Potent symbol of medical care
- Fan may also be helpful

Opioids

- Relief NOT RELATED to respiratory rate
- No ethical or professional barriers
- Growing evidence base -> opioids are standard of care for palliation of dyspnea
- Small doses
- Central and peripheral action

Nonpharmacological Interventions

- Reassure, work to manage anxiety
- Behavioral approaches, e.g., relaxation, distraction, hypnosis
- Physical therapy - breath & energy conservation
- Nonpharmacological Interventions
- Limit number of people in the room
- Open window

Nonpharmacological Interventions

- Eliminate environmental irritants
- Keep line of sight clear to outside
- Reduce the room temperature
- Avoid chilling the patient
- Introduce humidity
- Reposition - elevate the head of the bed, move patient to one side or other
- Educate, support the family

Nausea/Vomiting Assessment

- Review hospice diagnosis, comorbidities
- When did your nausea begin?
- What makes it worse/better?
- Related to food, position?
- What other symptoms do you have with it?

Nausea/Vomiting Assessment

- Sick contacts?
- What medications have you tried?
- Have you vomited? How often? Blood (bright red or coffee grounds) or bile?
- Are you moving your bowels?
- Explore life stressors, family conflicts, fear/worry

Nausea/Vomiting Physical Exam

- Vital signs
- Appearance - Color, signs of distress
- HEENT
- Heart and lungs
- Skin turgor

Nausea/Vomiting Physical Exam

- Abdomen - Bowel sounds, masses, distention, ascites
- Rectal exam if suspect constipation
- Extremities - Edema, perfusion
- Nausea is a subjective sensation, stimulation gastrointestinal lining, vestibular apparatus, cerebral cortex
- Vomiting - neuromuscular reflex

Causes of Nausea/Vomiting

- Metastases
- Meningeal irritation
- Movement
- Mental anxiety
- Medications
- Mucosal irritation

Causes of Nausea/Vomiting

- Mechanical obstruction
- Motility
- Metabolic
- Microbes
- Myocardial

Management of Nausea/Vomiting

- Dopamine antagonists
  - Haloperidol (Haldol)
  - Prochlorperazine (Compazine)
- Antihistamines
  - Diphenhydramine (Benadryl)
  - Meclizine
- Anticholinergics
  - Scopolamine

Management of Nausea/Vomiting

- Serotonin antagonists
  - Odansetron (Zofran)
- Prokinetic agents
  - Metoclopramide (Reglan)
- Antacids
  - Includes H2 blockers
  - Proton pump inhibitors

Management of Nausea/Vomiting

- Other medications
  - Steroids (dexamethasone)
  - THC
  - Benzodiazepines (lorazepam)

Management of Nausea/Vomiting

- Bowel regimen
- If obstruction
  - Consider venting gastrostomy tube
- If dehydration
  - Consider IV or SC fluids
- If large-volume ascites
  - Consider paracentesis
  - Indwelling Pleurex catheter

Terminal Agitation

- Thrashing or agitation which may occur in the last days or hours of life
- Broad differential, including:
  - Pain
  - Anxiety
  - Dyspnea
  - Delirium

Terminal Agitation

- Disturbance in consciousness/Attention
- Change in cognition - e.g.: memory, orientation, language
- Develops over a short period of time
- No safety awareness
- Hallucinations
- Fluctuating mood swings
- Abnormal body movements

Delirium is Common

- Up to 80% of people experience delirium during the final week of life
- 15 – 20% hospitalized cancer patients experience some delirium
- Delirium can be reversible in ~50% of episodes *(Lawlor et al. Arch Intern Med 2000;160:786-94)*

Differentiating Delirium from Dementia

Features	Delirium	Dementia
Onset	Acute	Insidious
Course	Fluctuating	Progressive
Duration	Days to weeks	Months to years
Consciousness	Altered	Clear
Attention	Impaired	Normal except in severe dementia
Psychomotor changes	Increased or decreased	Often normal
Reversibility	Usually	Rarely

Differentiating Delirium from Dementia

- Recognizing and naming delirium is the first step in its appropriate management

Causes of Delirium

- Medication-induced
- Dehydration
- Infection
- Pain
- Constipation
- Urinary retention
- Dehydration

Causes of Delirium

- Drug overdose/withdrawal
- Metabolic causes
- Hypoxia
- Cardiac event
- Environmental causes
- Emotional, spiritual, psychosocial stress
- Terminal delirium

Delirium Goals of Care

- Are the patient and caregivers safe?
- Does the patient appear in distress?
- Identify the cause

Delirium Treatment of Symptoms

- Look for underlying cause
- Calm, quiet, familiar environment
- Education, reassurance of caregivers
- Keep patient safe
- Correct hearing, visual impairments
- Beware of medication overuse. It can CAUSE and/or make delirium WORSE!
- Goal: find minimum effective dose to calm patient but avoid side effects

Antipsychotics

- Typical (older):
  - Haloperidol (Haldol) - drug of choice
  - Chlorpromazine (Thorazine)
- Atypical (newer):
  - Quetiapine (Seroquel)
  - Risperidone (Risperdal)
  - Olanzapine (Zyprexa)

Antipsychotics

- Anxiolytics:
  - AVOID - It may worsen delirium
  - Lorazepam (Ativan), etc.
- Last resorts:
  - Phenobarbital PR
  - Midazolam (Versed) SC/IV infusion
  - Propofol IV infusion

Follow-up Note: Paul

- No bowel movement x 1 week. Disimpacted & started on daily regimen. UTI diagnosed and treated with liquid Antibiotic. Had multiple doses of Ativan 2 mg q4 hours prn - weaned to 0.5 mg q4-6 hours prn. Created a calmer environment. Allowed Paul to express/use his energy safely. Haloperidol 0.5-1 mg SL q4-6 hours prn. In 2-3 days, Paul back to his baseline.

Syndrome of Imminent Death

- There are many physiologic changes in the last hours and days of life
- We need to understand the underlying pathophysiology in order to manage symptoms

Decreasing appetite and food intake

- Most dying patients lose their appetite
- Families and staff sometimes worry the patient is “starving to death”
- The body is unable to absorb and use nutrients
- Anorexia and resulting ketosis can lead to a sense of well being

Decreasing fluid intake and dehydration

- Most dying people lose their sense of thirst, but complain of dry mouth
- Dehydration may stimulate endorphin release that promotes the patients sense of well being
- Excess IV fluids can lead to pulmonary edema & dyspnea; ascites; anasarca; incontinence & skin breakdown

Cardiac dysfunction and renal failure

- As cardiac output and intravascular volume decrease there will be diminished peripheral blood perfusion
- Tachycardia, hypotension, peripheral cooling, peripheral and central cyanosis and mottling of the skin are normal

Cardiac dysfunction and renal failure

- Venous blood may pool along dependent skin surfaces
- Urine output will fall as perfusion of the kidneys diminishes. Oliguria or anuria is normal and IV fluids will not reverse the circulatory shut down.

Common Signs

- Loss of ability to swallow - buildup of secretions may lead to gurgling sounds
- Loss of sphincter control - incontinence of urine, stool
- Changes in breathing patterns - periods of apnea and/or Cheyne-Stokes

Effective Strategies for Communication with Patients and Families at End of Life

- Family challenges
- Effective tools for communication
- Responding to feelings
- Challenged families
- Strategies
- Team communication
- Concluding meeting
- Team debriefing

Family Challenges

- New experience for most families
- Significant amount of medical information provided to families which can be difficult to understand
  - Multiple MD's
  - Medical "jargon"
  - Anger at medical providers re: delayed diagnosis or ineffective treatment

Family Challenges

- The information provided at this time can be confusing, powerful and upsetting
- Families are dealing with the **reality** of their situation - including their emotional turmoil, frustration and grief
- Will be faced with making significant difficult decisions

Family Challenges

- People are not always “at their best” during crisis
  - Cannot always “hear” all information because of anxiety, shock, etc.
- Long standing problems or issues within the family may surface

Family Challenges

- Families may struggle with guilt and/or regret
  - Keeping patient in hospital/or Hospice House
  - Placing patient in nursing home
  - Not fulfilling patient's wish to go home
  - Financial decisions
  - Rapid decline of patient

Family Challenges

- Families may have discordant views about treatment plans and EOL care
  - Code Status
  - Health Care Proxy Issues
  - Aggressive Treatment
  - Financial concerns

Family Challenges

- Beliefs and behaviors concerning EOL care can differ greatly within families
  - Religious
  - Cultural
  - Ethical issues
  - Values

Effective Tools for Communication

- Prepare
  - Gather all pertinent medical, psychosocial information
  - Communicate with IDT team
  - Make sure all are “on the same page”

Effective Tools for Communication

- Be specific about GOALS of meeting
  - What is important for team to know
  - Anticipate goals/questions from family
  - Why Hospice? Why now?

Effective Tools for Communication

- Determine who's to be present
  - Which family members - who is spokesperson
  - Patient? (Why or why not)
  - Which IDT team members - have multidisciplinary input

Effective Tools for Communication

- Choose appropriate environment to talk
  - Privacy
  - Quiet space
  - Large enough room
  - Tissues available

Effective Tools for Communication

- Give yourself adequate time
- Decide (before hand) on facilitator for meeting
- Announce time frame for meeting - “We have about an hour”
- Ask family what **their** goals are for meeting - Information needed? Concerns, questions?
- Inform family as to goals of team

Effective Tools for Communication

- Encourage full family participation
  - Encourage expression of feelings
  - Encourage questions, concerns
- Answer questions in clear, “family friendly” language (not clinical)
- Frequently “check-in” for families’ understanding of information
- Use of “teach back”

Effective Tools for Communication

- Stay focused on Goals of meeting – gently bring back discussion
- Allow expression of discordant views
  - Often no “right or wrong” perspective
  - What would the patient want?
- Focus on patient’s wishes

Responding to Feelings

- Be prepared for displays of emotions
- Give people time to react (especially if they are not aware of the gravity of their illness)
- Listen quietly - allow for SILENCE
- Use non-verbal communication
- Allow time for people to verbalize their feelings and ask questions

Responding to Feelings

- Ask people to describe their feelings:
  - Can you tell me how you are feeling about what I just said?
  - What worries you the most?
  - What are your hopes?
  - What's most important to you right now?

Responding to Feelings

- Normalize, name and validate myriad of feelings
  - Anger, frustration, sadness, grief, shock
  - “Sounds like this has been a very recent diagnosis and you have a lot of mixed feelings”.
  - ”Perfectly normal to feel angry and sad and confused”.

Responding to Feelings

- Affective responses - Tears, anger, sadness, love, anxiety
- Cognitive responses - Denial, blame, guilt, disbelief, fear, loss, shame, intellectualization
- Basic Psycho physiologic response - Fight or flight

Challenged Families

- Mental Illness
- Personality disorders
- Substance Abuse
- Disenfranchised populations
  - Underserved populations
  - Poverty
  - Language barriers
  - Legal issues

Challenged Families

- Cognitive issues
  - Can’t understand or process information
  - Thought distortions
- Emotional issues (Mental health)
  - Anxiety, agitation, depression
  - Can prevent appropriate behaviors/responses
  - Can prevent full comprehension of situation
- Poor support systems
- Financial concerns

Strategies for communication with challenged families

- Access community resources already in place - Case manager, social worker
- Invite family's support person/friend/advocate
- Encourage each participant to express feelings
- Name and validate specific emotions expressed
- Rules/Boundaries for Meeting

Strategies for communication with challenged families

- Keep focus on GOALS of meeting
- Expressions of anger, frustration need to be appropriate
- No one allowed at meeting who is “under the influence”
- Stay FOCUSED on goals of meeting - Do not allow tangential long-standing issues to be discussed
- Team support

Strategies for communication with challenged families

- Frequent and open communication
  - Avoid miscommunication
  - Avoid splitting (staff cohesiveness)
  - Keep focused on goals of care
  - Provide information re: specific mental illness or personality disorder, etc.

Team Communication

- Access supervisory support
- Request consultation
- Utilize community support services familiar with family's issues
- Allow for support for team members
  - To vent - verbalize frustrations
  - To avoid judgment and negative attitudes

Things to Consider

- It is okay to not have all the answers
- Provide a good role model of calmness to de-escalate the feelings of crisis
- Respect the coping behaviors of patients and families without judgment
- Respect patient and family wishes regarding care and comfort measures

Things to Consider

- Long standing conflicts or tensions will probably not resolve now - resist the temptation to be a “fixer”
- Encourage families to express their feelings in a supportive, non-judgmental way
- Remind families of outside resources
  - Support groups
  - Church
  - Community organizations

Concluding the Meeting

- Ask group if they have any more concerns/questions
- Ask participants to summarize their understanding of conclusions, recommendations, etc.
- Explore if everyone has had a chance to participate

Concluding the Meeting

- Provide contact information for families if they have further questions - contact person for team (Name, phone #)
- Summarize specifically what's been addressed, decided, understood
- Set up an additional appointment when further questions can be asked, if necessary
- Encourage self-care

Concluding the Meeting

- Conclude meeting with reminders to families about self-care:
  - What is your support system?
  - How do you practice self-care?
  - How can team support you at this time?
  - Anything important for team to know?

Team Debriefing

- After meeting concludes
- Team impressions
- Any follow-up
  - Who is responsible?
  - Communication with outside sources?
  - Communication within agency?