Last Hours of Living

Disclosures

No conflicts to disclose

Objectives

- Describe how to assess and manage physiological changes and symptom management
- Describe how to support the patient, family and caregivers during an expected Death
- Identify the importance of practicing good self care

Audience Response

Who had been with your patient when they died and expected death?

How many where present in your patients home?

Last hours of living

- **How we die**
  - < 10% suddenly
  - > 90% prolonged illness
- **Last opportunity for life closure**
- **Little experience with death**
  - exaggerated sense of dying process

Preparing for the Last Hours of Life . . .

- Time course unpredictable
- Any setting that permits privacy, intimacy
- Anticipate need for medications, equipment, supplies
- Regularly review the plan of care

. . . Preparing for the Last Hours of Life

- **Caregivers**
  - o awareness of patient choices
  - o knowledgeable, skilled, confident
  - o rapid response
- **Likely events, signs, symptoms of the dying process**
- **Patients and families want you to be knowledgeable in educating them on what to expect during the final hours**

Calling in Hospice

- **Medicare Hospice Benefit**
  - o Routine Benefit cover care for the patient in their "home".
    - Home
    - Long-term care facility
    - private pay in facility
    - assisted living
  - o Cover
    - 100% of medication related to terminal diagnosis
    - DME

Hospice continued . . .

- **Routine Hospice covers**
  - Nursing care, home health aids, chaplains and volunteers.
  - They also can provide physical therapy, occupational therapy, and speech therapy
  - goal is to keep patient functional and safe, not to be “rehabilitated”
- **Patient is able to continue to see attending of record**
- **Does not require patient to be homebound**

Hospice Levels of Care

- **Routine**
- **Respite: provides 5 days of care in a facility for caregiver break**
- **GIP: general in-patient level of care**
  - o When intensive medical and nursing care is needed to manage EOL symptoms.
  - o Usually provided in hospitals or a hospice facility
- **Continuous care: when intensive nursing and supportive care needs to be provided in the patients home. Hospice staff will be present continuously, but requires greater than 50 % nursing coverage**

What Hospice Does Not Provide

- **Room and board in a facility**
  - This can result in financial hardship for families
  - Custodial care of any kind
  - Medications not related to terminal diagnosis

Video

Physiologic Changes During the Dying Process

- Increasing weakness, fatigue
- Decreasing appetite / fluid intake
- Decreasing blood perfusion
- Neurologic dysfunction
- Pain
- Loss of ability to close eyes

Decreasing Appetite / Food Intake

- **Fears: "giving in," starvation**
- **Reminders**
  - o food may be nauseating
  - o anorexia may be protective
  - o risk of aspiration
  - o clenched teeth express desires, control
- **Help family find alternative ways to care**

Decreasing fluid intake . . .

- **Oral rehydrating fluids**
- **Fears: dehydration, thirst**
- **Remind families, caregivers**
  - o dehydration does not cause distress
  - o dehydration may be protective

. . . Decreasing fluid intake

- **Parenteral fluids may be harmful**
  - o fluid overload, breathlessness, cough, secretions
- **Mucosa / conjunctiva care**

Decreasing Blood Perfusion

- Tachycardia, hypotension
- Peripheral cooling, cyanosis
- Mottling of skin
- Diminished urine output
- Parenteral fluids will not reverse

Neurologic Dysfunction

- Decreasing level of consciousness
- Communication with the unconscious patient
- Terminal delirium
- Changes in respiration
- Loss of ability to swallow, sphincter control

Weakness / Fatigue

- **Decreased ability to move**
- **Joint position fatigue**
- **Increased risk of pressure ulcers**
- **Increased need for care**
  - activities of daily living
  - turning, movement, massage

Communication With the Unconscious Patient . . .

- Distressing to family
- Awareness > ability to respond
- Assume patient hears everything

. . . Communication With the Unconscious Patient

- **Create familiar environment**
- **Include in conversations**
  - assure of presence, safety
- **Give permission to die**
- **Time to be alone**
- **Touch**

Terminal Delirium

- **Look for cause and reverse if possible within the goals of care**
- **If caught early can be managed**
- **Medical management**
  - Benzodiazepines
  - lorazepam, midazolam
  - Neuroleptics
  - haloperidol, chlorpromazine
- **If unmanaged can lead to seizures then death**
- **Family needs support, education**

Changes in Respiration . . .

- **Altered breathing patterns**
  - o diminishing tidal volume
  - o Apnea
  - o Cheyne-Stokes respirations
  - o accessory muscle use
  - o last reflex breaths

. . . Changes in Respiration

- **Fears**
  - suffocation
- **Management**
  - family support
  - breathlessness

Loss of Ability to Swallow

- **Loss of gag reflex**
- **Buildup of saliva, secretions**
  - scopolamine to dry secretions
  - postural drainage
  - Positioning
  - suctioning

Loss of Sphincter Control

- Incontinence of urine, stool
- Family needs knowledge, support
- Cleaning, skin care
- Urinary catheters
- Absorbent pads, surfaces

Pain . . .

- **Fear of increased pain**
- **Assessment of the unconscious patient**
  - persistent vs fleeting expression
  - grimace or physiologic signs
  - incident vs rest pain
  - distinction from terminal delirium

. . . Pain

- **Management when no urine output**
  - o stop routine dosing, infusions of morphine
  - o breakthrough dosing as needed (prn)
  - o least invasive route of administration

. . . Pain

- **Routine pain medications should be continued**
- **Family is educated on how to assess patient for signs of pain**
  - o Increase respiratory rate or increased work of breathing
  - o Restlessness and moaning
  - o Facial grimacing

Medications

- **Limit to essential medications**
- **Choose less invasive route of administration**
  - buccal mucosal or oral first, then consider rectal
  - subcutaneous, intravenous rarely
  - intramuscular almost never

Expected Death

As Expected Death Approaches . . .

- **Discuss**
  - o status of patient, realistic care goals
  - o role of physician, interdisciplinary team
- **What patient experiences ≠ what onlookers see**

. . . As Expected Death Approaches

- Reinforce signs, events of dying process
- Personal, cultural, religious, rituals, funeral planning
- Family support throughout the process

Signs That Death Has Occurred . . .

- Absence of heartbeat, respirations
- Pupils fixed
- Color turns to a waxen pallor as blood settles
- Body temperature drops

. . . Signs That Death has Occurred

- **Muscles, sphincters relax**
  - release of stool, urine
  - eyes can remain open
  - jaw falls open
  - body fluids may trickle internally

Families need verification the patient has died, even though they know.

What To Do When Death Occurs

- Don’t call 911
- Whom to call
- No specific “rules”
- Rarely any need for coroner
- Organ donation
- Traditions, rites, rituals

After Expected Death Occurs . . .

- Care shifts from patient to family / caregivers
- Different loss for everyone
- Invite those not present to bedside

Bereavement Care

- **Bereavement care**
- **Attendance at funeral**
- **Follow up to assess grief reactions, provide support**
- **Assistance with practical matters**
  - o redeem insurance
  - o will, financial obligations, estate closure

Loss, Grief, Coping

- **Grief = emotional response to loss**
- **Coping strategies**
  - conscious, unconscious
  - avoidance
  - destructive
  - suicidal ideation

Normal Grief

- **Physical**
  - hollowness in stomach, tightness in chest, heart palpitations
- **Emotional**
  - numbness, relief, sadness, fear, anger, guilt
- **Cognitive**
  - disbelief, confusion, inability to concentrate

Complicated Grief . . .

- **Chronic grief**
  - o normal grief reactions over very long periods of time
- **Delayed grief**
  - o normal grief reactions are suppressed or postponed

. . . Complicated Grief

- **Exaggerated grief**
  - o self-destructive behaviors eg, suicide
- **Masked grief**
  - o unaware that behaviors are a result of the loss

Tasks of the Grieving

1. Accept the reality of the loss
2. Experience the pain caused by the loss
3. Adjust to the new environment after the loss
4. Rebuild a new life

Grief Assessment

- Grief can show in all areas of life—obesity, for example may be an indication of negative effects of prolonged grief
- Chronic grief can result in delayed reactions—may take several years for the overt symptoms of chronic grief to be consciously felt
- Exaggerated symptoms to relatively minor problems can be a sign of grief overload

Assessment of Grief

- **Repeated assessments**
  - o anticipated, actual losses
  - o emotional response
  - o coping strategies
  - o role of religion
- **Interdisciplinary team assessment, monitoring**

Grief Management

- **If reactions, coping strategies appropriate**
  - Monitor
  - Support
  - Counseling
  - rituals
- **If inappropriate, potentially harmful**
  - rapid, skilled assessment, intervention

Summary

- Families rely on you to prepare them for what is to come
- They fear abandonment from the primary providers

Self-Care

Self-Care

- Our daily work includes a lot of grief and loss—must be proactive in mediating the long terms effects of coping with chronic grief and loss
- Self care in general will help—caring for yourself physically, mentally and spiritually

Audience Response

- How many of you feel you have a good work-life balance?
- Who gives out their personal cell number to patients and families?

Signs and Symptoms of Stress

- Headache
- Musculoskeletal complaints
- GI problems
- Palpitations
- Sleep disturbances
- Emotional disturbances
- Fatigue and exhaustion
- Family or co-worker conflicts
- Change in sexual behavior

Definition

- **Definition: World English Dictionary**

  compassion fatigue — *n* the inability to react sympathetically to a crisis, disaster, etc, because of overexposure to previous crises, disasters, etc

Other related Terms:

- Empathy Fatigue
- Burnout
- Vicarious Traumatization
- Secondary Traumatic Stress Disorder
- Just plain sick ‘N’ tired

The Stats

- 76% of 2,500 clergy members survey were overweight or obese compared with 60% in general population
- More than 60% of helping professionals have a trauma history of their own—we enter the field to make a difference, to give back, and share from our own life experiences
- 59% of mental health professionals were willing to seek help vs 15% of law enforcement

Compassion Fatigue vs Burnout

- **Burnout---is a term that describes low job satisfaction, feeling powerless, overwhelmed, depleted and frustrated by their work environment**
- **Many persons in 'non-helping' jobs may experience burnout, who are not particularly in a traumatic environment**

Compassion Fatigue vs Depression

- Employees who considered most of their days to be quite a bit or extremely stressful were over three times more likely to suffer a major depressive episode, compared with those who reported low levels of general stress
- Chronic Compassion Fatigue can lead to depression, anxiety, addiction, mental and physical illnesses if left unchecked

Can We Prevent Compassion Fatigue?

- Compassion fatigue has been described as “the cost of caring” for others in emotional pain
- Compassion fatigue is an occupational hazard
- Compassion Fatigue is a disorder that affects those who do their work well
- Caring for others is both my calling and my cross to bear

Things to Consider

- Prevention is ideal, but may not be realistic
- Know your own patterns
- Be confident, you got this!
- Find the ‘off switch’ in your head, and by all means shut it down when you leave the office
- Be human, respect your emotional limits
- Their emergency is not necessarily your emergency!
- Give yourself some grace!

Coping With the Burnout Effect

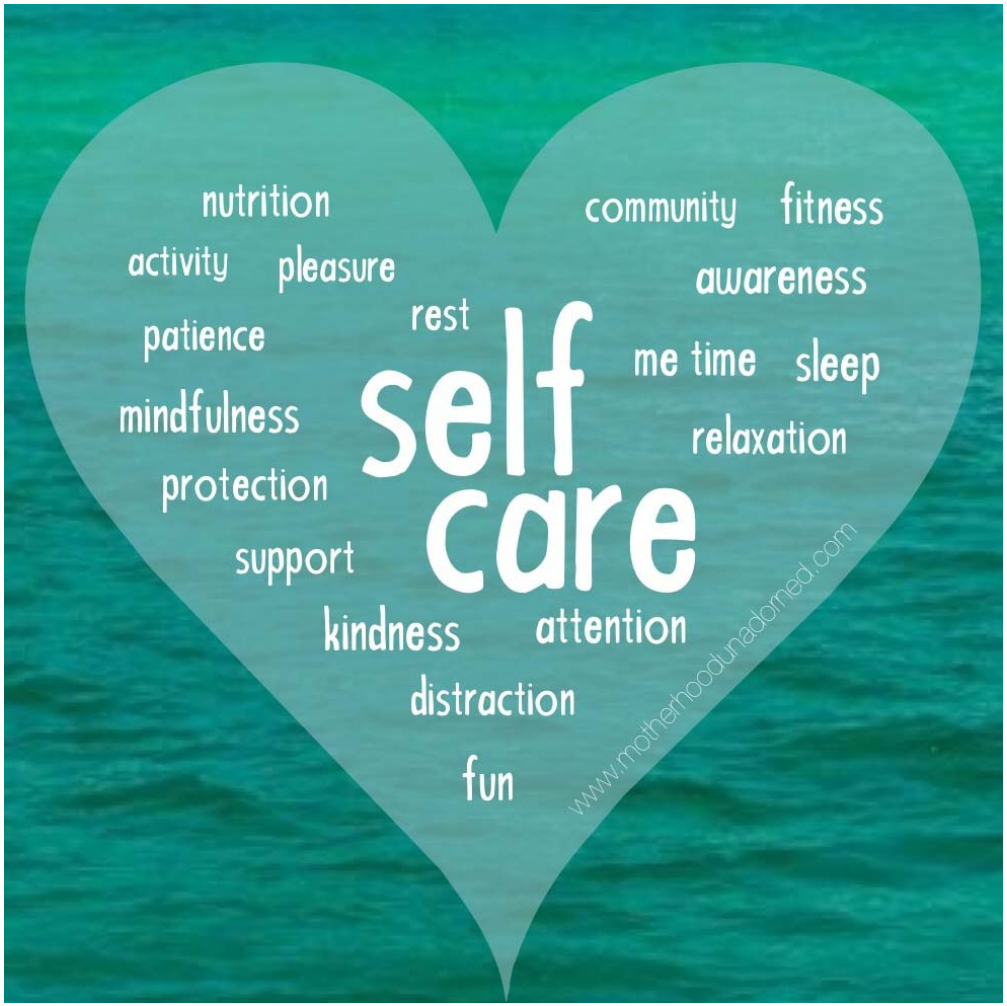
- **Burned out caregivers are ineffective caregivers**
- **Burned out caregivers need relief and nurses do not always given themselves permission for “down time”, time away from loss**

Coping With the Burnout Effect

- When others around you offer to help—accept their offers to lighten your load
- Seek out your agency's employee assistance program
- Participate in agency rituals for coping with grief
- Taking excellent care of your body, mind and spirit helps mediate the effects of chronic grief

Summary

- If we don't take care of our selves we can not take good care of our patients
- We can't be present with our families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