Palliative Care

**Goal** of this program is to enhance the understanding of needs of the dying person. It is designed to augment one's existing knowledge and experience in this field. The individual resident’s (aka client) care plan, the operating policies and procedures of the operator and, the direction of the nurse in charge is the primary source for resident specific care directives.
What is palliative care?

“Palliative care as a philosophy of care is the combination of active & compassionate therapies. It is intended to comfort & support individuals and their families who are living with a life threatening illness. It strives to meet the physical, psychological, social, emotional & spiritual needs while remaining sensitive to personal, cultural and religious values.”
Our role......
your thoughts?

Consider that we need to be aware of our own fears, values, beliefs and then, separate our own agenda from that of the person we are supporting.
Who is involved?

Physicians, pharmacist, spiritual support, nursing team, hospice, recreation team (yes), you (yes!)

Who else?________________
What does the dying person need as they deal with changes?
What changes?

• Change to their body
• Change to how they perceive the future
• Change in level of independence
• Change in own attitude & attitude of those around them (perhaps or, one’s perception)
• Change in relationships with others
Needs (rights) of the dying person

- to be free of pain yet alert
- to have the companionship of family & friends
- to be accepted as the person they have always been
- to maintain their individuality and be part of decisions
- not to die alone
- not to be a burden to their family or caregivers
- to be cared for & remembered with love & respect
- to have familiar things (people too) around them
- to have their family be alright, to be able to continue living and loving after their death
- The need to be cared for by compassionate, sensitive, knowledgeable people
- The need to have questions answered honestly
- The need to be cared for by compassionate and knowledgeable people
Tips to support client’s needs:

• pictures of family and pets
• pictures of client when they were healthy
• personal belongings which reflect things meaningful to them
• helping them say goodbye
• help them not to feel like a burden
• generous visiting flexibility, lower bed rails
• facilitate open dialogue
• help family acknowledge fears, anger
“To fill with courage”

• Your words can be therapeutic, must be sincere!
• “I admire the way you are handling this”
• You have been coping with so much, so well – what is your strength?
Coping Strategies: *We typically cope...*

- we all cope differently, we cope as we have historically coped with life’s challenges
- affected by attitude, previous crisis, level of support, family experiences, general health, strength, pain level etc.
- some families pull together & function better during these times, other “fall apart” and have diverse needs
- analogy coping to a door- can’t be wide open or shut tight all the time
Positive reframing:

• We can’t cope any longer” ➔ “How have you coped so far”
• “I’m terminal” ➔ “You’re living with a terminal illness”
• “I hate complaining” ➔ “We need to know so we can help”
• “He’s giving up” ➔ “He’s letting go.”
Use of metaphors

• can be useful to help client talk about issues which are perhaps too difficult for them to address directly. Through the use of metaphors you could ask:
  – “IF you became weaker what would you want/need?”
  – “IF you were going to die (or go away soon) what would you want done, said?”
  – “IF you were living in a country under siege and could be taken away at any moment, what would you likely ensure you say to your family, in case there was no other opportunity?”
Tips:

• listen & gently encourage openness
• answer honestly including, “I don’t know”
  – Then...
  • encourage family dialogue-involve family where possible in client care
  • help ID realistic short term goals
  • control symptoms
  • address or find resource to address spiritual issues
  • relaxation RX
  • Consider timing of serious discussions
“The friend who can be silent with us in a moment of despair or confusion, who can stay with us in an hour of grief and bereavement, who can tolerate not knowing or healing, and face with us the reality of our own powerlessness. That is the friend who cares.”

Henry Nouman
Be especially careful of your first words, contact with client and family. Your words and actions are long remembered especially as people’s emotions may be very fragile.
A Caring Touch can often be more eloquent (and helpful) than words.
Relaxation Tips:

• visualization, music, healing hands, pets, laughter, videos, timely visits/outings

• reasonable projects, easy to pick up & set down again, pleasing.

*seek options for client to enjoy meaningful work or, take actions that bring closure for himself and others
What could the dying person fear?

- loneliness
  - pain
- loss of control
- loss of choice
  - indignity
- being forgotten
- dying alone
- concern for loved ones left behind
What could you fear?

• not having the “right” answer or saying the “wrong” thing
• crying in front of client/family/co-workers
• fear of one’s own mortality
• fear of the body
• That personal conflicts or unresolved issues will be triggered
• some questions have no answers, you do not need to have the answer

• beware of distancing behavior-normalizing, selective attention, changing topic, physical stance ie: GP delivering news

• non-verbal distancing includes poor eye contact, closing eyes or looking away, barriers (desk), displacement gestures (picking at clothes, sheets), chin down or neck rubbing (feeling critical of content of conversation)
being SOLER
• What about communication support for fellow residents?

• What about communication with and closure for staff?
The Grieving Process:

Symptoms of grief:

• grief is normal & healthy “a healthy response to loss, grief takes energy & lasts longer than most expect.
• in families where there has been a long illness, family may have already started & moved through some stages of grief
• factors that influence the intensity and duration of grief include age & relationships of those involved, previous experiences with loss, degree of emotional and material dependency on the dying person, nature of the illness or trauma (sudden or traumatic ie disfiguring), religious beliefs and other social supports
The Grieving Process:

Children & grief:
- children are better able to grieve if dealt with sensitively but honestly. A child will often imagine things far worse than the reality (Great imaginations). Attempts to protect a child from situations may only add to their confusion & distress. They may feel resentful in time if not included “If only I had known.”
- children are great at masking their emotions too and often peers are ill equipped to help
The Grieving Process:

Anticipatory grief:

• *It starts with the terminal diagnosis*
The Grieving Process:

Physical symptoms of grief:

• 95% sleep disturbances
• 80% diarrhea or constipation
• 50% nausea, irregular heartbeat or other cardiac dist.
• 80% wake early
• also menstrual changes, sexual dysfunction, depression, weight loss or gain
The Grieving Process:

Psychological symptoms of grief:

- 80% guilt or feeling of futility
- 75% edgy, easily irritated
- 70% cry often
- 90% poor concentration, indecisive
- 60% poor memory

*5 times higher death rate for bereaved during 1st year*
“Cocooning”
The terminal stage where the dying person may draw into themselves, physically limited energies, emotionally & spiritually drawing away.

Help families understand so they don’t feel rejected & can assist the client to say goodbye (give permission).

Encourage family to support what client has started.
PHYSICAL NEEDS/SUPPORT of the Dying Person

Mouth care:
3 common problems

1. **Dry mouth** - meds, thrush, oral breathing (mouth care Q2H) & frequent sips of fluid, ice chips

2. **Sore mouth** – thrush, ill fitting dentures, ulcers, gingivitis

3. **Coated tongue** – unpleasant for client & causes halitosis, predisposes to thrush
Rx: swab with fresh pineapple juice (no sugar) or hydrogen peroxide (lifts debris), ice chips, sugarless candies (sugar promotes thrush/yeast), popsicles esp. if made from juice! Fruit nectars may be tolerated if juice isn’t.
ALERT!

NO fluids once decision has been made to withhold. This increases need for excellent mouth care
Mouth care continued:

- lip balm
- avoid glycerin swabs for long term use
- report white spots on red tongue (Thrush), cracks, swollen tongue
- provide regular mouth cleaning, dentures Q8hrs, & anytime if client has vomited
- avoid commercial mouthwashes as may contain alcohol, too strong (can use 1 tsp. baking soda in a cup of warm water.)
Eye care:

• eyes can be very dry & painful, avoid glaring lights
• use artificial tears Q2H (refer to plan of care)
• report any drainage or inflammation to the nurse
• gentle cleansing
Skin care & positioning:
- advise client before you start
- gentle, soothing
- short nails, remove your jewelry
- change positions (approx. Q2 H BUT be mindful of timing) ensure proper body alignment, support of affected limbs
- can raise head of bed to relieve SOB & minimize gurgling
- sheepskin, air mattress, petroleum pad
- **gentle** massage improves circulation to areas, observe & report any blanching, redness, breakdown
- watch especially bony prominence-elbows, scapula, coccyx, heels, ears, scalp
- cream ok but not in creases, Zinc oxide can be helpful to protect skin
- hygiene important for comfort & to minimize odors
Odor control:

• clean area generating the odor rather than masking odor!
• STAT bagging of and disposal of soiled items
• odor sponge, odor gone, Gentle Assurance
• bowl of vinegar in room, cat litter (activated charcoal) under bed
Body wastes:

• clean promptly, double bag, use incontinent pads, gloves, aprons
• if at risk for hemorrhage suggest dark sheets, towels, have lots of soakers handy
• note renal output, observe for urine retention
• if client incontinent but able to participate, toilet on regular schedule but offer alternatives to increase comfort and reserve energy
Nausea/anorexia:

- approx. 60% - try to find cause, document volume, consistency and colour of vomit
- can be conditioned response after chemotherapy
- drugs can cause but also help Rx, diet, positioning
- ensure client’s mouth is cleaned prn, remove any garbage, soiled linens asap
- if client experiences hiccups, elevate head of bed to decrease exertion used to breathe report to nurse
“If you can keep the client’s bowels moving, it’s like you can walk on water”
Constipation:

a HUGE source of discomfort and medical complications!

• causes:
  – anorexia
  – abdominal and/or rectal pain
  – obstruction
  – dehydration
  – Restricted mobility
  – medications especially narcotics
• start aggressive bowel routine early (before problem starts) – stool softener, laxatives, diet, ambulation, hot drink (coffee great) to aid peristalsis
• where feasible, increase fluids, roughage (fruitlax, fruit, prunes, etc.)
• record BMs & report concerns esp. distention, increased confusion, nausea & vomiting
PAIN

ALL pain
is personal and subjective-
it is always real to the person experiencing it
Pain can be:
- sharp or dull
- acute or chronic
- continuous or intermittent
- annoying or excruciating
- stabbing, throbbing
- shallow or deep

May be unrelated to the reason one is dying
- ie) arthritic resident
Historically we check vitals –

*pulse, BP, respiration, etc.*

We don’t ask enough about pain

*How/when and why should we ask?*

What if the client continues to deny the pain?

*Consider that pain in Greek is “poine” (penalty)*
Assessing Pain

*keep nurse informed of observations

A sk about pain regularly (but don’t wake to ask)

B elieve the client/family in their report of pain

C hoose pain control options appropriate for that client & setting

D eliver interventions in a timely, logical manner

E mpower clients and their families
Typical non-verbal signs of pain:

- Tense facial expressions
- Constant fidgeting
- Nervous habits - lip and nail biting
- Unexplained withdrawal
- Strained or high-pitched tone of voice
- Clenched hands/ hunched shoulders
- Guarding
- Grimace upon movement
Key to pain control is to identify the cause/ source(s)
Reasons the dying person might feel pain:

- pressure from tumors/obstruction
- organ secretion (e.g., minimal food intake, significant heartburn)
- chronic illnesses (e.g., arthritis - now not moving enough)
- tumor impacting bones (spontaneous fractures) or nerves
- fever related pain
- pain associated with loss
- side effects of chemo or radiation
- pressure sores
- edema (ensure skin is moisturized) - diuretics often don’t help in this case
Our Role

Help client and family be comfortable accepting pain management. Many, especially seniors fear addiction.

Help understand that valuable energy (theirs) and valuable time with family can be lost due to consumption of pain- can fill one’s consciousness.
Pain is well controlled in approximately 90% of cases, 5% of the remaining 10% can be in real “Pain”
Total pain is the sensation of pain combined with emotional distress, the #1 psychological component of pain is **FEAR!**
Pain Issues:

• Pain control **goal** is to be pain free & alert!, know your client, continually monitor-observe for pain (not everyone will voice it).
Pain Issues:

- Factors that **DECREASE** a client’s pain threshold:
  
  *anger, anxiety, boredom, discomfort, guilt, fatigue, insomnia, family upsets, remembering past pain, sadness, anticipating future pain*
Pain Issues:

Factors that **INCREASE** a client’s pain threshold:

*aqua sleep/rest, pain control, symptom control, trust, being cared for & allowed to care for others, companionship, spiritual support, relaxation RX, art, a sense of purpose, music, pets, diversion activities.*
Pain RX Considerations

• radiotherapy to shrink tumor to reduce discomfort, blockages
• nerve blocks for localized acute cancer pain (may be short or long lasting)
• neurosurgery can be an option if above not effective
• hypnosis, massage, supportive devices to support limb etc.
• mentholated creams, heat or cold, TENS
• prayer, meditation, imagery, therapeutic touch
Oxygen:

- **MAY** be used as comfort measure
- ensure mask or cannula properly positioned
- ensure skin around nose/mouth kept dry & free of irritation
- check for pressure areas around ears & scalp
- Secaris helpful as barrier cream
As death is imminent:

Signs & Symptoms of approaching death...
• increasingly difficult to rouse or

• restless/ agitated/ confusion

• often see one pulling at sheets- reaching into the air

• may suddenly (and unexpectedly) sit up

• may have fixed stare

• pulse fluctuates dramatically
• cooling and mottling of extremities

• irregular respirations – apnea up to and even exceeds 60 seconds

• gurgling sound in back of throat

• cheyne stoking

• decreased urine output
What if family asks you...

“How much longer?...”
“The Agonal phase of death”

Dying is like shutting down a large factory filled with engines, assembly lines and giant boilers. Everything does not suddenly go quiet when the “off” switch is pushed.

Instead the machinery creaks and moans as it slows to a halt.
Death is as primitive as birth

Researchers believe at the end, the body releases endorphins - hormones that block pain and give one a sense of tranquility and joy. Whether accurate or not, may bring peace of mind to family.
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<th>%</th>
<th>Ambulation</th>
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<th>Self-Care</th>
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<td>Unable to Do any Work</td>
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Recommended reading:

• *Final Gifts (Understanding the Special Awareness, Needs and Communication of the Dying)* by Maggie Callahan & Patricia Kelley

• *Final Journeys - a Practical Guide for Bringing Care and Comfort at the end of Life* by Maggie Gillan

• Books by Eda LeShan particularly beneficial for children/youth and their peers

Books by Elizabeth Kubler-Ross
“There is a land of the living & a land of the dead & the bridge is love” ...a.k.a. YOU!

Thornton Wilder