# BUILDING YOUR TOOLBOX: TOP 10 "MUST-KNOWS" FOR PROVIDING CARE IN THE FINAL DAYS AND HOURS

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# OBJECTIVES

By the end of the presentation participants will:

a) Be able to identify changes associated with end of life (EOL)
b) Be able to recognize and have strategies to manage symptoms, and possible situations in the patients home, associated with EOL
c) Be familiar with Expected Death In The Home (EDITH) protocol and role of care providers in the time after death

# KEY POINTS

PPS

Appetite/Swallowing

Transition to SC

Bowel function at EOL

Bladder function at EOL

Neuro-Cognitive Changes

Respiratory Changes

EDITH

Pronouncement of Death

Post-Mortem Care

# PALLIATIVE PERFORMANCE SCALE (PPS)

Developed

- Based on Karnofsy performance scale which is utilized in oncology (dating back to post WW1 era)
- Adapted to be applicable to patients receiving palliative care, across settings
- 200+ publications, validated tool

Purpose

- Common language
- Prognostication

# The Palliative Performance Scale (PPSv2)

| | Palliative Performance Scale (PPS) | | | | | |
|---|---|---|---|---|---|---|
| | PPS level % | Ambulation | Activity & Evidence of Disease | Self-Care | Intake | Conscious Level |
| Stable | 100 | Full | Normal activity & work<br>No evidence of disease | Full | Normal | Full |
| | 90 | Full | Normal activity & work<br>Some evidence of disease | Full | Normal | Full |
| | 80 | Full | Normal activity with effort<br>Some evidence of disease | Full | Normal or Reduced | Full |
| Transitional | 70 | Reduced | Unable normal job/work<br>Significant disease | Full | Normal or Reduced | Full |
| | 60 | Reduced | Unable hobby/house work<br>Significant disease | Occasional Assistance | Normal or Reduced | Full or Confusion |
| | 50 | Mainly Sit/Lie | Unable to do any work<br>Extensive disease | Considerable Assistance | Normal or Reduced | Full or Confusion |
| | 40 | Mainly in Bed | Unable to do most activity<br>Extensive disease | Mainly Assistance | Normal or Reduced | Full or Drowsy<br>+/- Confusion |
| EOL | 30 | Totally Bed Bound | Unable to do any activity<br>Extensive disease | Total Care | Normal or Reduced | Full or Drowsy<br>+/- Confusion |
| | 20 | As Above | Unable to do any activity<br>Extensive disease | Total Care | Minimal sips | Full or Drowsy<br>+/- Confusion |
| | 10 | As Above | Unable to do any activity<br>Extensive disease | Total Care | Mouth care only | Drowsy or Coma<br>+/- Confusion |

# HOW TO READ PPS(V2)

- Read LEFT to RIGHT
  - Leftward parameters take precedent
- HORIZONTAL best fit
- Clinician judgement overrides ambiguity
- Based on client CAPABILITY/POTENTIAL versus what is observed

# APPETITE/INTAKE AT EOL

Natural decline in intake as patient approaches EOL (often preceded by loss of appetite);

Reasonable to expect just small sips/bites in final days, decreasing to sips, and then mouth care

As energy depletes, energy to coordinate muscles of swallowing decline.

Difficulty swallowing pills, sips

Can signify transition to more imminent EOL.

# MODIFICATIONS

Modifications aim to minimize the energy it takes to consume the item

Puree textures, liquids

Straws vs spoon vs sips

BUT!!

Focus of food as a function of quality of life

- Tastes that evoke pleasure, memories, feel good in the mouth
- De-emphasize nutrition, pressure to meet minimums

# DE-PRESCRIPTION

Planned and supervised process of dose reduction, or stopping of medication that no longer of benefit

Often a process that could take place throughout trajectory, but can be highlighted in final phase of life

Assessing value of each medication in relation to: symptom management, promotion of quality of life, ease of reduction/withdrawal BALANCED WITH

- Limited desire to swallow
- Inability to swallow

# SUBCUTANEOUS ADMINISTRATION OF MEDS

Intermittent subcutaneous injection

- PRN's
- Scheduled dosing + PRN

CADD

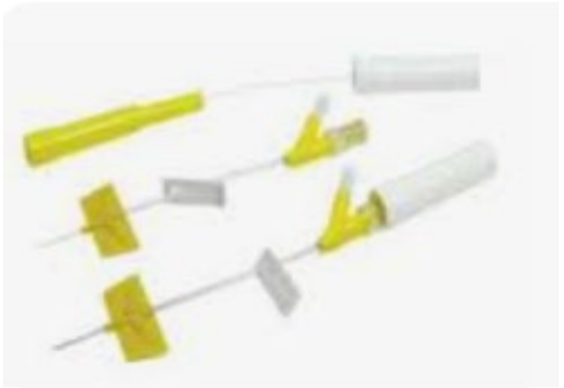
- Provide continuous hourly dosing of medication + availability of PRN
- In EOL context may ease care-giving strain

# SC LINE INSERTION

Devices:

- Saf-T intima
  $3.26
- Infusion set
- Intermittent

- CLEO
  $8.10
  Infusion set



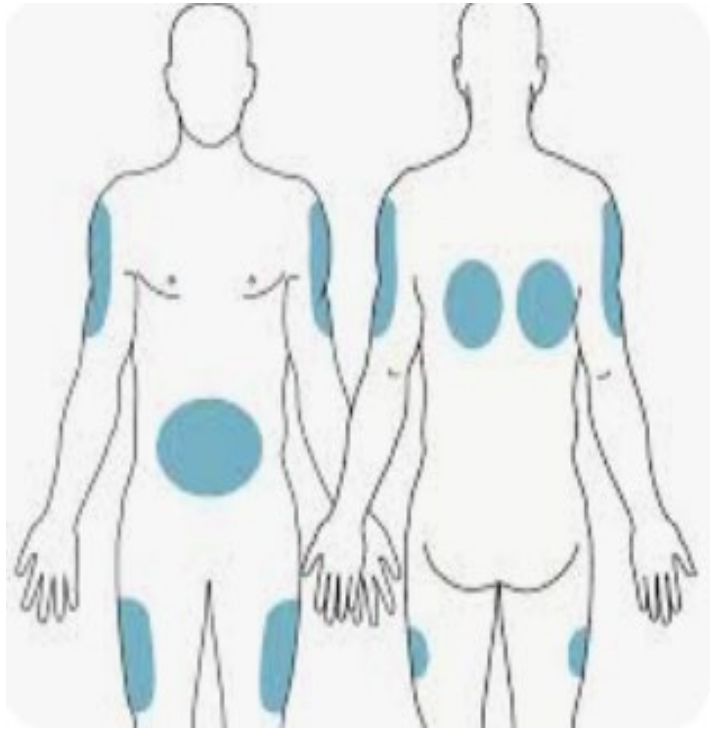
# SAF-T INTIMA INSERTION

Prepare skin

- alcohol (w/ chlorhexidine preferred), allow to dry!

Prime set

- dedicated lines = prime with medication
- shared line = prime with NS
- policies per individual organization



# SAF-T INTIMA INSERTION

Prepare to insert

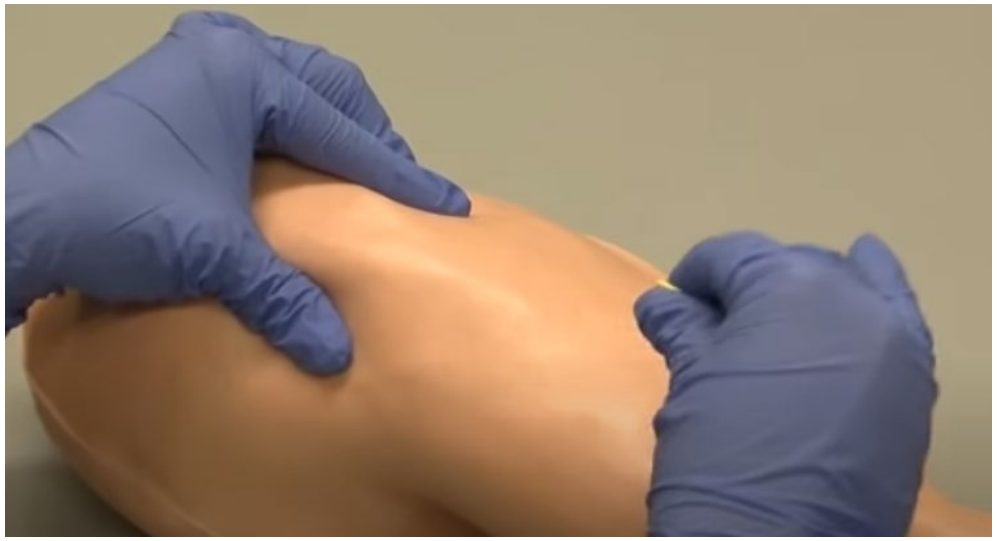
- bevel up (twist guidewire), dimples down
- Anchor site

Insert

- 30 degree angle insertion
- Remove guidewire

Secure

- transparent dressing, labelled



# BOWEL FUNCTION AT EOL

Constipation at EOL:

- Dehydration
- Medication
- Immobility/inactivity/decreased strength for defecation
- Inability to continue laxative regime (ie: inability to swallow tablets, volume of polyethylene glycol (PEG/Restoralax))
- Environmental/Psychological factors

BUT!!

- Bowel lining shed + emptying of colon = reasonable to expect ongoing bowel movement, despite minimal to no intake

# ASSESSMENT OF BOWELS

History: usual bowel pattern

Medication: Continue bowel regime as long as possible (PO)

Exam: auscultate, palpate, DRE, observe (refractory agitation vs comfort)

Intervention: dulcolax suppository, glycerin suppository, Fleet Enema; aggressive bowel management often not necessary when client is comfortable

# URINARY CHANGES AT EOL

Production of urine will slow down

Characteristics of urine change: clear, yellow, amber, brown, concentrated odour

New incontinence (often functional)

# URINARY RETENTION

Inability to pass urine from bladder via urethra

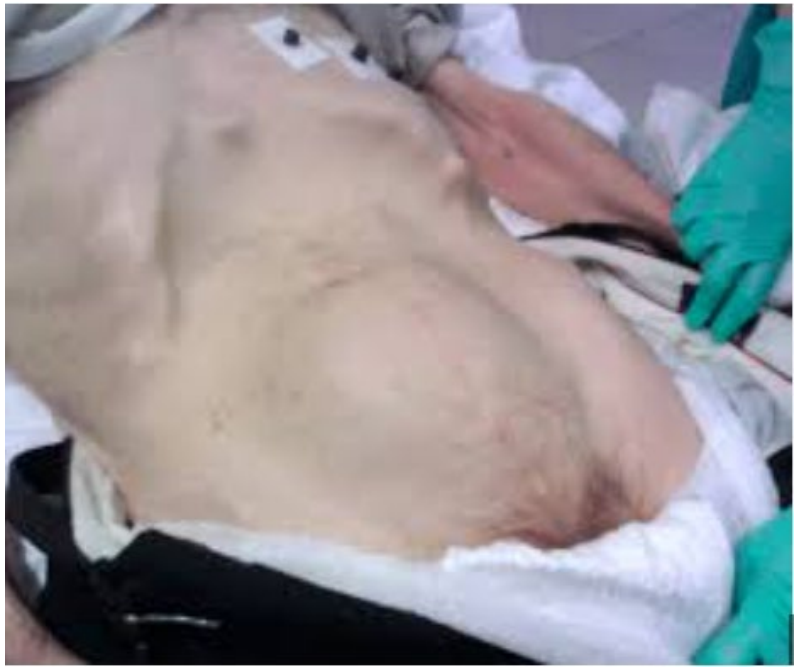
Can lead to pain, agitation

Etiology:

- Obstruction
- Constipation
- Medication

Intervention:

- Catheter insertion



# NEURO-COGNITIVE CHANGES AT EOL

Decreasing Level of Consciousness

- increased time sleeping
- decrease time interacting
- window for meaningful awake time may be closing

Terminal Delirium

- between 25-85% of patients exhibit signs and symptoms of “terminal agitation” days preceding death
- attempts at correcting underlying source of symptoms if appropriate
- range of severity = range of intervention

# TERMINAL DELIRIUM

Mild:

- may be managed with environmental modifications
- “Quiet your ripple”

Moderate:

- antipsychotic medications (methotrimeprazine/Nozinan, haloperidol/Haldol)

Severe:

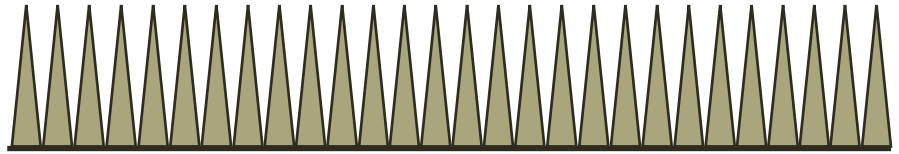
- antipsychotic medications + benzodiazepine (midazolam/Versed)
- doses proportional to symptoms; continuous infusion

# RESPIRATORY CHANGES AT EOL

- diminishing tidal volume ( depth)
- apnea ( pauses)
- upper airway secretions
- accessory muscle use
- last reflex breaths

Cheyne-Stokes

Kussmaul



“Agonal” / Ataxic

# UPPER AIRWAY SECRETIONS

Pooling of saliva/mucous in oropharynx
- Normal physiologic secretions that we would normally swallow or expectorate

Vibration of air (breath) moving across pooled secretion
- Gurgling, “death rattle”

Repositioning
- Side-lying
- Towel placed under cheek

Medication
- Anticholinergic medications
- Do not work on fluids that are present, but may prevent worsening
- Diuretic in case of pulmonary edema

# UPPER AIRWAY SECRETIONS

Address concerns

- “gasping”
- “drowning”
- Mechanism of medications

Normalize

- In EOL phase patient comatose, unaware of secretions; “snoring”
- Medications to reduce anxiety/concern in place, but not necessarily needed if patient comfortable

# EXPECTED DEATH IN THE HOME (EDITH)

EDITH protocol

- End of life planning tool: identifies team/key players, end-of-life plan
- Allows for pronouncement of death by visiting nurse (Home Care Nurse), transport of decedent to funeral home without Form 16 (MCOD)
- Patient's MRP will f/u with funeral home to complete Form 16

EDITH protocol

- Requires signed DNR-C
- Funeral home information
- Confirmation of pronouncement plan with MRP

# EDITH

Role of the Nurse:

- Visit or Shift nursing provider will be first call at time of death, or present in home to pronounce
- Attend home to do death pronouncement
- Fill in funeral home transfer form
- Assist family to contact funeral home

# DEATH PRONOUNCEMENT

Observe:

- Movement of breathing (cessation of) for 3 minutes
- Pupils fixed, dilated

Palpate:

- Absent radial pulse

Listen:

- Apical Heart Sounds—3 minutes
- Breath Sounds—3minutes

# DEATH PRONOUNCEMENT

Document:

S: called to home to pronounce death. Family report patient last breath ~2200hrs.

O: No movement of breathing observed
Eyes open, pupils fixed, non-reactive to light
No apical HR x 3mins

A: patient deceased

P: Lines removed, F/C removed. Funeral home transport form completed. Assisted family with call to funeral home. Deceased left in home, in care of family.

# MEDICAL CERTIFICATE OF DEATH (MCOD)

Completed by Physician, or NP (if involved in circle of care)

Where EDITH is in place, deceased can be moved to funeral home WITHOUT a signed MCOD; signee to follow up with funeral home within 24hrs after death to arrange the MCOD

MCOD contains information about immediate cause of death, AND information on contributing factors. Important for collection of statistics

Available in electronic form and can easily be completed from home/office in a timely fashion

# CORONER INVOLVEMENT

In palliative population this is likely to be an exception

- Immediate cause of death result of accident
- Death did not follow expected trajectory
- Death in Group Home environment (under ministry of social services)
- Suspicion of foul play

Nurse may be called to pronounce death, but if coroner involvement deceased should be left in found state (ie: Subcut lines in place, foley catheter in place etc). Coroner will review case with MRP and decide if appropriate to investigate.

If Coroner investigation to take place: they will attend home, and complete MCOD.

# POST-MORTEM CARE

Individualized needs

Traditions, Rites, Rituals

Rare cases: coroner involvement

Removal SC lines, foley

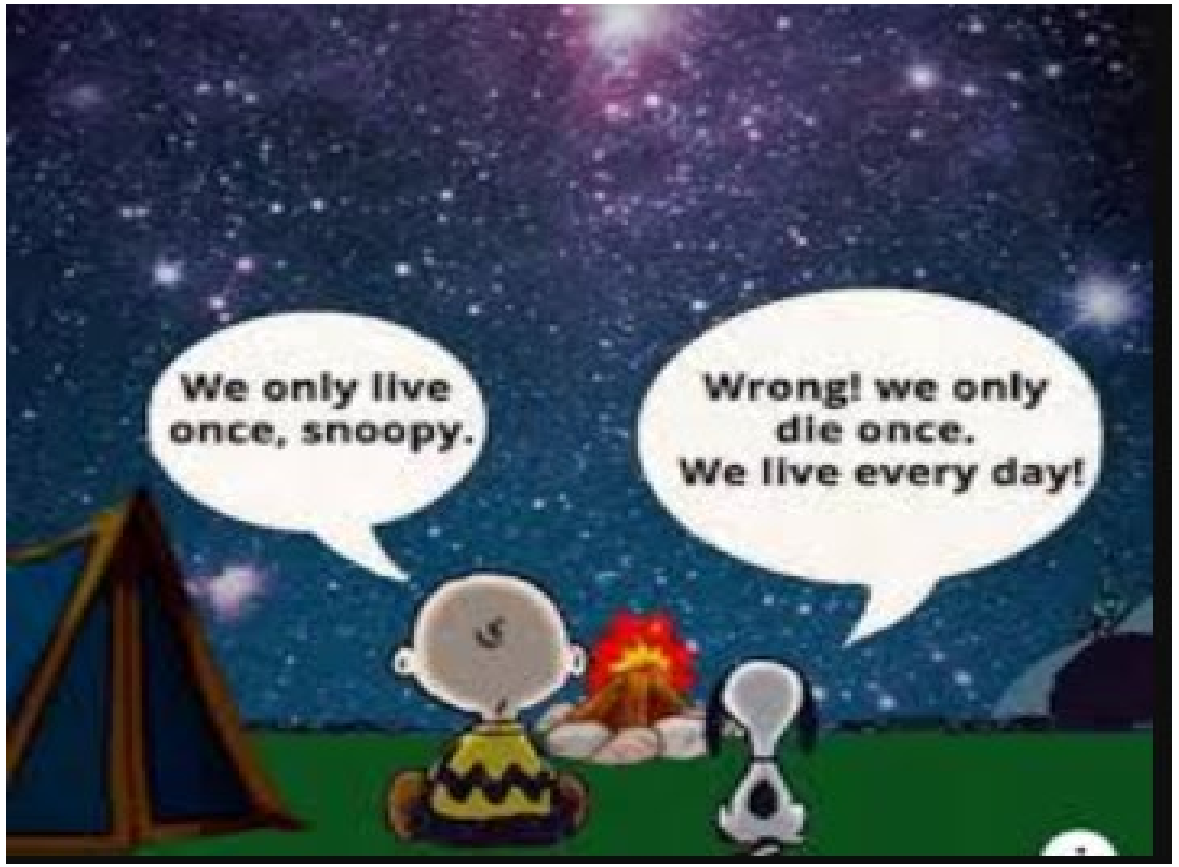
Wash up

Incontinence care/dressing

Positioning

Funeral Home

# THANK YOU


We only live once, snoopy.
Wrong! we only die once. We live every day!