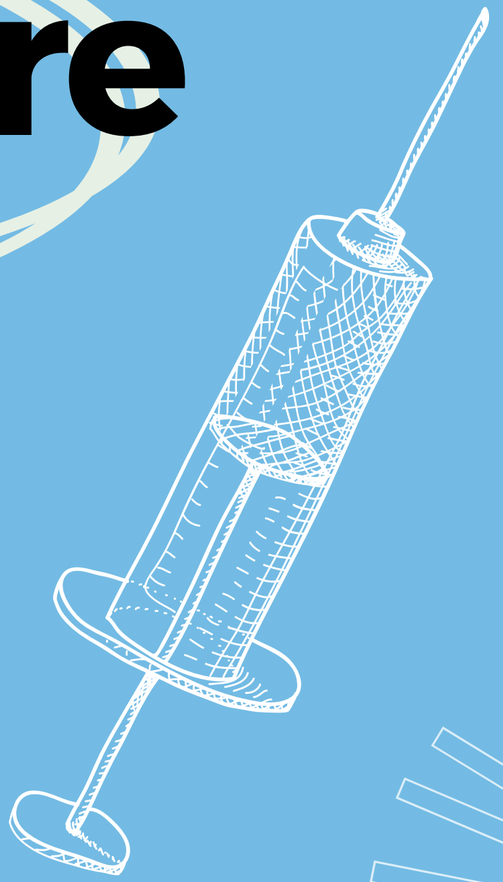
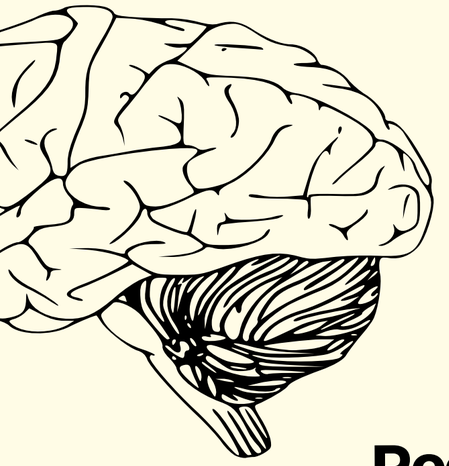
End Of Life Care

PRESENTED BY

NURUL IZZA BINTI YUSUB





Content

Recognizing Dying

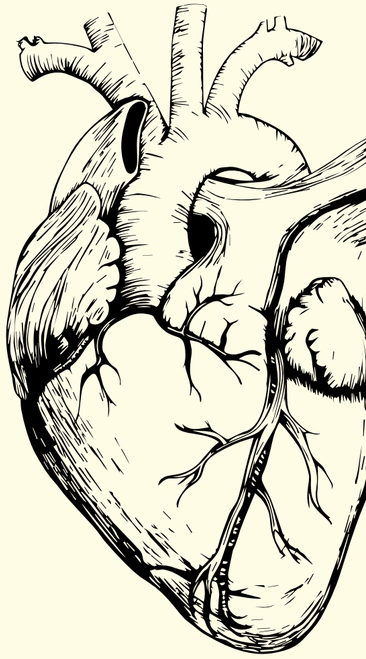
- Prognostication factors for patient with serious illness
- The dying process- final days/ hours signs
- The clinical changes that occur in the dying phase.

Care in the dying phase

- Pain
- Terminal respiratory secretion
- Restlessness/ delirium
- Nausea and Vomiting
- Oral care.

Others

- Some Ethical Issue in EOL



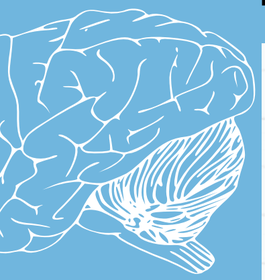
Prognostication

" the skill of predicting survival or outcome of a situation"

- prognostication is an essential tool to use when making clinical decision.
  - help us to plan individualized care for our patient.
  - guide our communication regarding the futility of treatment at end of life
  - help us to make clear ethical decision regarding the treatment that we are going to give to our patient

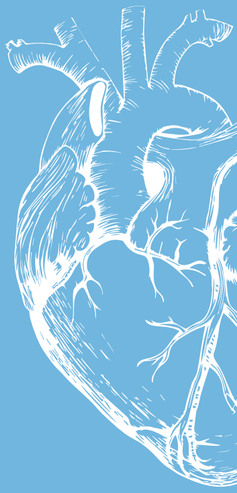
Handbook of Palliative Medicine Malaysia (2016)

Disease Trajectory



1. **DISEASE TRAJECTORIES IS RELATED TO THE NATURAL HISTORY OF THE DISEASE.**

   - not all patient have the same disease trajectory.
   - different category of illness have different trajectory
   - looking at the relation between patient's functional status (ECOG/ KPS) over time

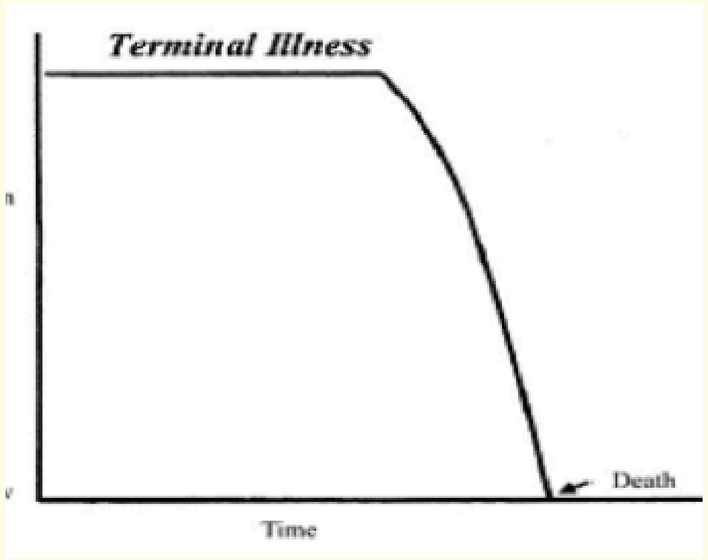


OVERALL, THERE ARE 3 MAIN TRAJECTORIES OF PATIENTS WITH CHRONIC INCURABLE DISEASE

Disease Trajectories

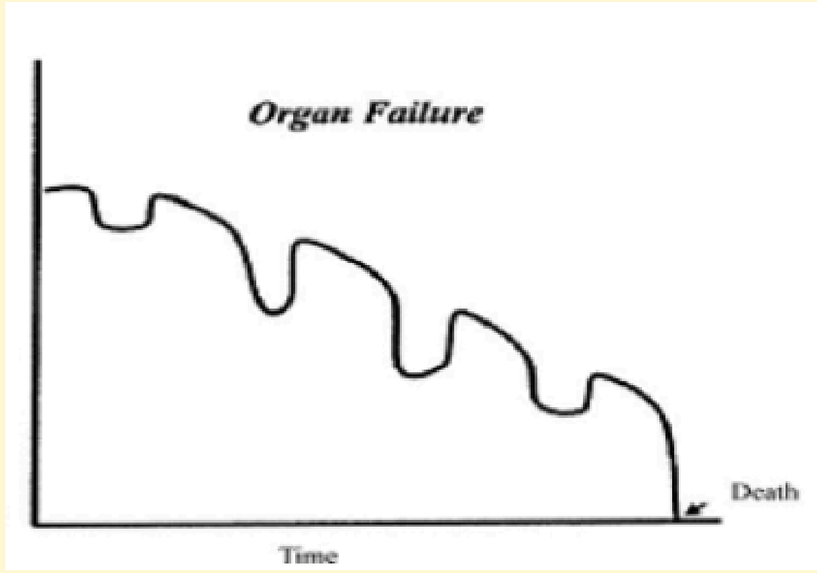
*functional status vs time

Incurable Cancer



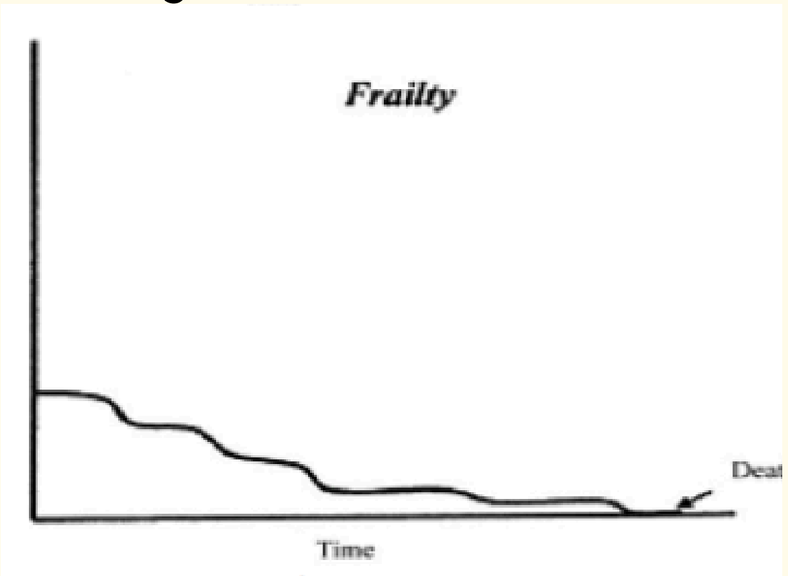
Short period of evident decline

Chronic Organ Failure



Long term limitation with serious episodes that may cause emergency hospital admission

Stroke / Dementia/ Frailty



Prolonged dwindling over the years

- onset could be deficit in functional capacity, speech , cognition

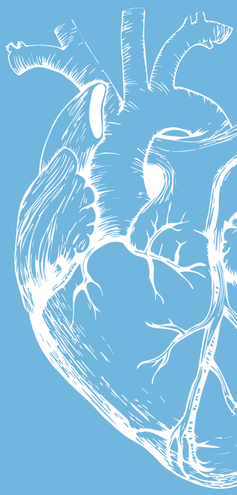
Murray et al, 2005

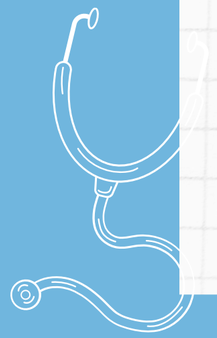
Prognostication

PRESENTED BY
OLIVIA WILSON

BASED ON THE SIGNS THAT WE SEE FROM PATIENT, SOMETIMES WE CAN PREDICT HOW LONG THE PATIENT MAY HAVE.

- based on patient's disease trajectory
- take into consideration of pt's characteristic.
- do not use exact amount of time, instead give a time frame when communicating prognosis.





Recognizing dying

Terminal phase :

“ It is the period when there is day-to-day deterioration, particularly of strength, appetite, and awareness. This may unfold gradually over days or weeks, or occur precipitously following an unexpected event, e.g. stroke”

Oxford Handbook of Palliative Care, (2019)

Priorities of care in this phase:

recognize the likelihood that pt is dying, and to communicate this sensitively to the family

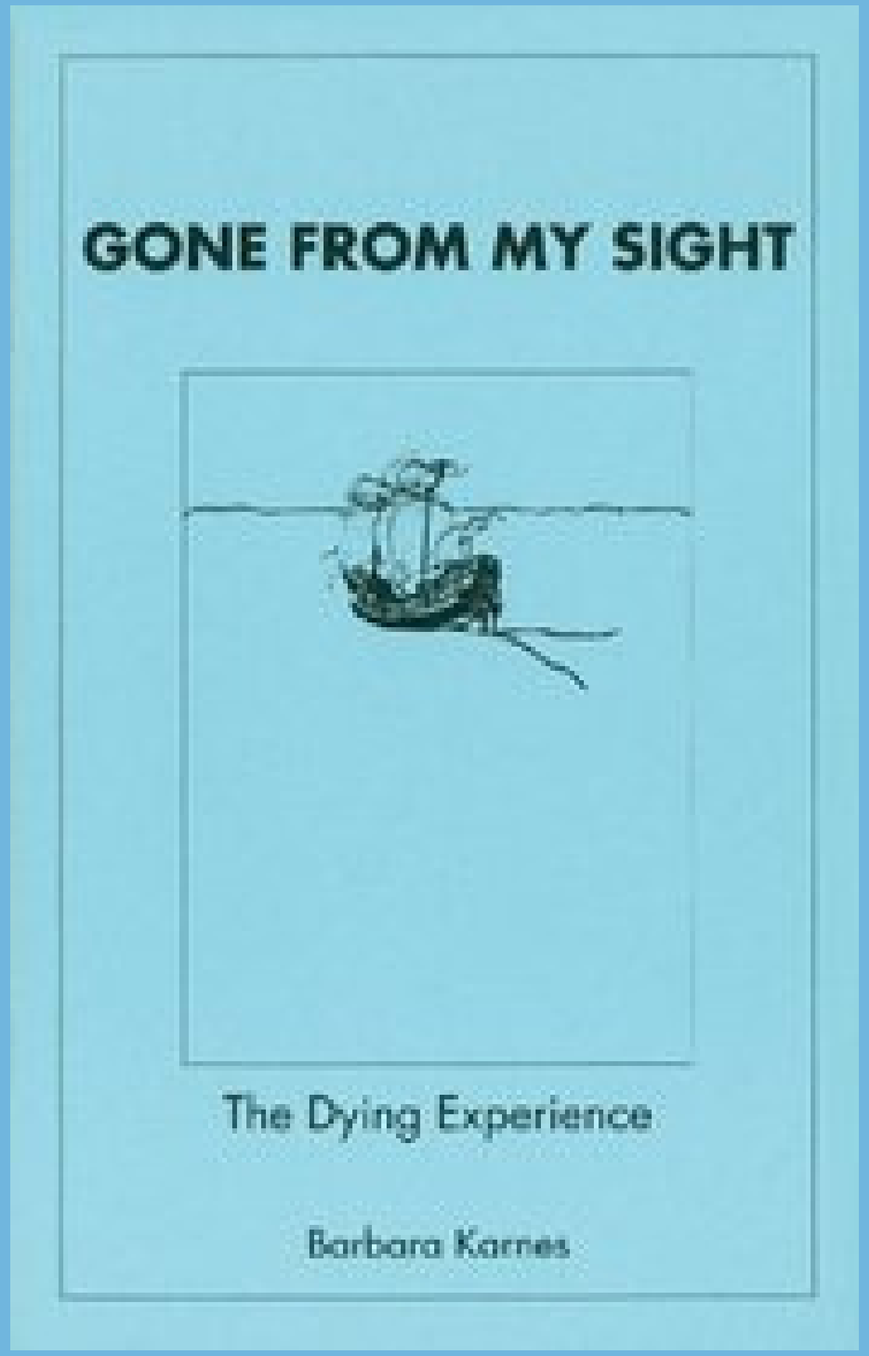
Individualized plan of care is agreed on, coordinated and delivered with compassion.

- food and drink
- symptom control
- psychological/ spiritual/social support

Explore what pt and family member need and attempts to meet these as far as possible.

include the dying person and the family in decision about treatment and preferences for care

- Eg : EOL place/



" People don't die like they do in the movie"

short weeks to days

- Pt become more weaker and fatigue easier
- Hallucination- some patient may report seeing children, friends or family member that have passed away
- Sleeping more.
- Needing more assistance in doing ADL
- Withdrawal more from others
- Loss of interest
- Start to have difficulties to swallow (dysphagia) especially to food, chocked when drink clear fluid.
- Bitemporal wasting

short days

- ECOG 4
- slow to arouse with stimulation, only brief period of wakefulness
- more episode of dysphagia.
- delirium- pt may start to picking up their clothes, or the bedsheet. Hands reaching up
- sleep with eyes half close
- agitation.(terminal restlessness)
- changes in breathing pattern - Cheyne-stoke, apnea, or irregular breathing
- loss of bladder and bowel control

Hours

- Coma
- Fever
- Altered respiratory pattern - gasping, period of apnea, or irregular breathing
- mottled extremities, cold extremities
- “Death Rattle”- pooled oral secretion that are not cleared due to loss of swallowing reflex

LOOK OUT FOR REVERSIBLE SYMPTOMS THAT MAY CAUSE PATIENT TO SHOW THE SYMPTOMS

- eg: Not every symptoms that you see in patient who are weaker or have sudden deterioration in consciousness level is due to the dying process.
- Rule out any reversible symptoms (infection, drug effect, hypercalcemia, electrolyte imbalance, hypoglycemia, constipation ect)

Assestment

1. **EXAMINATION IS KEPT AT MINIMUM TO AVOID UNNECESSARY DISTRESS**

   observe for any non verbal indication of discomfort.

2. **CONTINUATION OF SYMPTOM RELIEF**

   All medication for pain, dsypnea, and nausea should continue even in terminal phase.

   - when patient unable to swallow- SC route will be used in equivalent dose

3. **MEDICATION WITH NO BENEFIT AT THIS PHASE SHOULD BE STOPPED**

   eg : antihypertension, antiplatelet, statin, vitamin should be stopped, discuss this with doctors and advocate for patient's comfort.

Symptom management at EOL

Pain

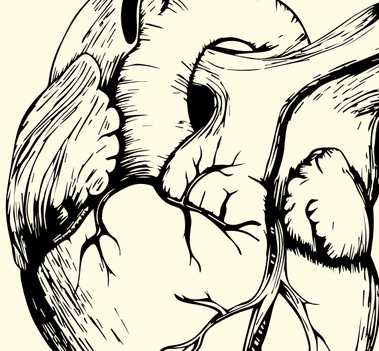
Dsypnea

Nausea

Restlessness

Dry mouth

Gurgling sound when breathing



Pain

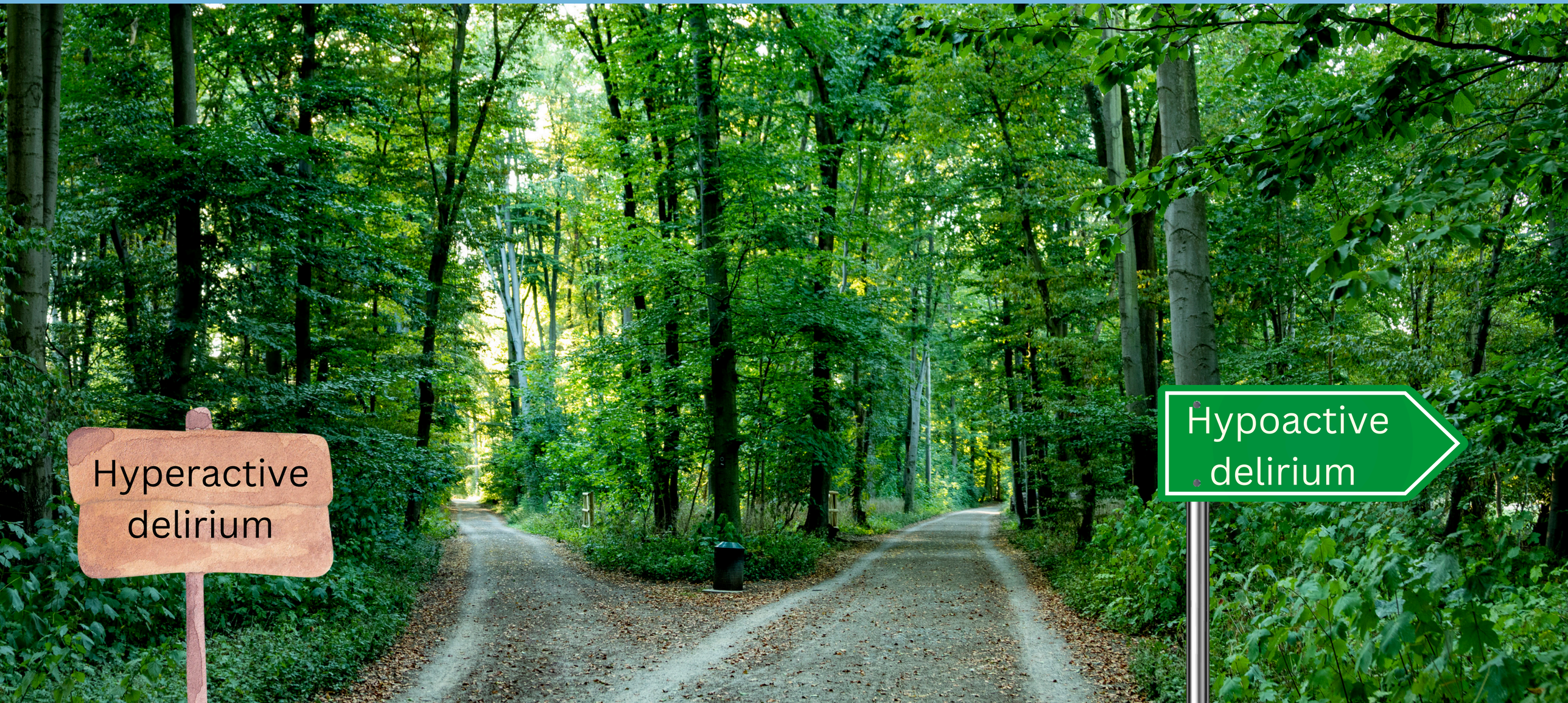
- Dying is not necessary painful.
- Not every patient who are dying requires morphine or any other pain medication
- Disease (like cancer) causes patient to have pain
- Look for signs of pain
  - Persistent or just a fleeting expression
  - Grimace or physiologic sign
  - Incident vs rest pain
  - Is it pain or is it Delirium?

- Patient's pain, dyspnea, nausea, seizure should still be managed even when they are in terminal phase and less responsive.

- If patient unable to swallow, change to SC route/ buccal

- **NEVER EVER CRUSH OR CUT OR DISSOLVE LONG ACTING OPIOID (MST tablet, OXYCONTIN) to give to patient even if they have NG tube**
    - **change long acting opioid to patch or using syringe driver or continuous infusion**

Delirium at EOL



Delirium

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HYPERACTIVE DELIRIUM

“The Difficult Road to Death ”

Sign of active dying

Irreversible

Hyperactive

Support pt, family & caregiver

Hyperactive terminal delirium

Where possible, rule out reversible cause of delirium and restlessness.

- full bladder
- pain or other symptoms
- fever

Goal : keep patient comfortable and settle

Benzodiazepine
- Midazolam/ Lorazepam

Antipsychotic
- Haloperidol

SEVERE AGITATION
- may require hospital admission for drugs like Levopromazine/ phenobarbitol

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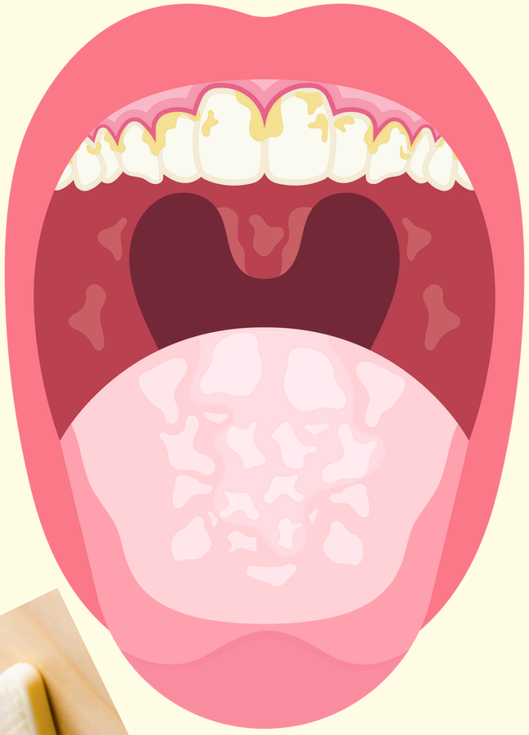
OLIVIA WILSON

Rattling/ Phlegmy sound when breathing

aka " Death rattle "

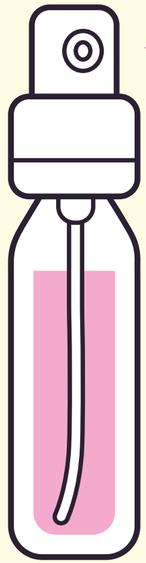
- Due to secretions collecting in airways- pt cannot cough out or swallow it down as usual
- Important to EDUCATE family that the secretion are not causing suffocation, chocking or distress (Although it distress family to hear it)



Oral Care

Often missed, but very important for patient care

- poor oral hygiene and dry mouth can cause discomfort
- DRY MOUTH- due to decrease oral intake , stomatitis, mouth breathing, and side effect of opioid.



Educate

- Teach and encourage family to clean the patient's mouth with cotton/ 'Good Morning towel' (not microfiber towel), or baby toothbrush dipped in sodium bicarbonate solution
- Keep mouth moist with small amount of fluid using spray bottle, syringe or cotton ball dipped with some water.
- Apply vaseline/lip balm on the lips,and can apply thin layer of butter/ honey on the inside of mouth to reduce dryness

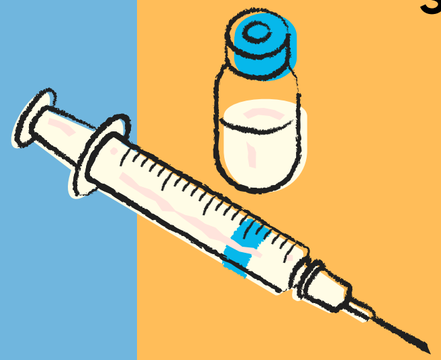
Death Rattle management

Non-Pharmacological

Elevate patient's head by 30 degree or put patient in lateral position

- to allow drainage of the secretion

Pharmacological



Anti-cholinergic agent to dry secretions.

- SC hyosine Butylbromide (buscopan) 60-240mg/24hours or 20mg prn
- SC glycopyrrolate 600-1200mcg/24hours CSCI or 200-400mg tds

Suctioning often not recommended

- Usually deep suctioning will not improve secretion
- cause further distress to patient

Its only useful for pooled secretions in oral cavity

Medication at EOL

Limit to essential medication

- Opioid (Morphine, Oxynorm, fentanyl patch)
- Benzodiazepines (Midazolam/ Lorazepam)
- Anticholinergic (Buscopan)
- Antipsychotic (Haloperidol)

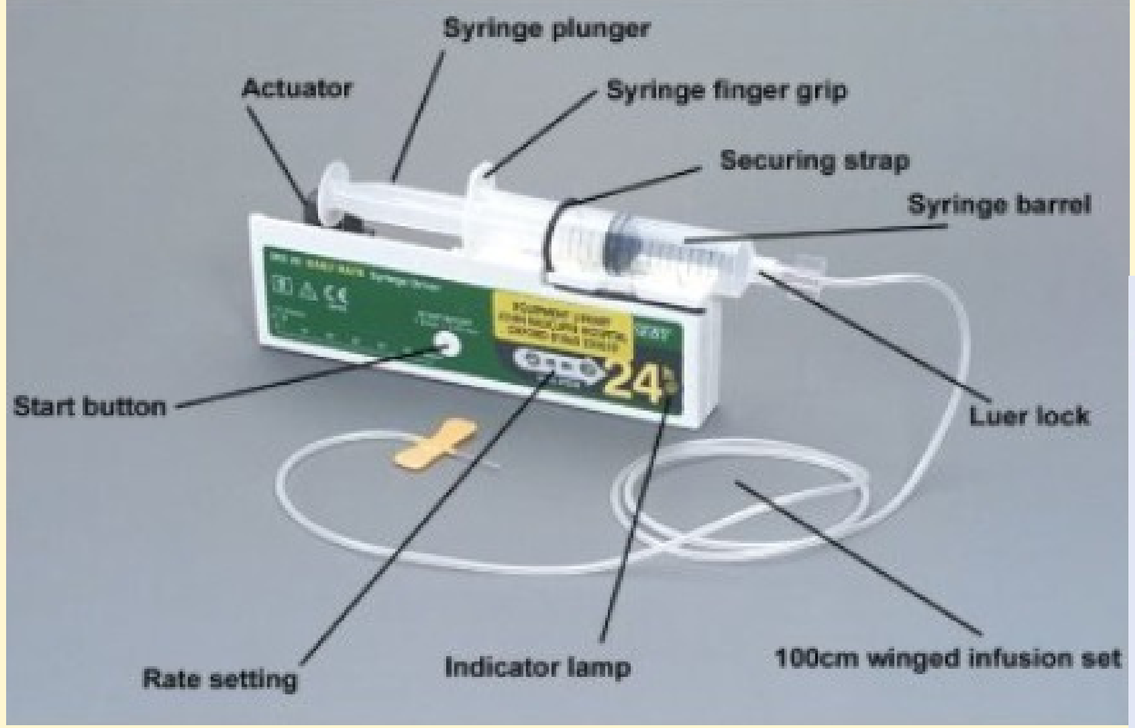
Choose less invasive route of administration

Buccal mucosa
Subcutaneous

- AVOID intramuscular- more painful for patient

Provide a clear written instruction of dose and indication if pt managed at home

- The one caring for patient / collect medication at hospital may not be the one caring for pt at home
- provide reinforcement of the information that was conveyed.
- Reduce confusion and fear of giving medication to patient



Subcutaneous injection

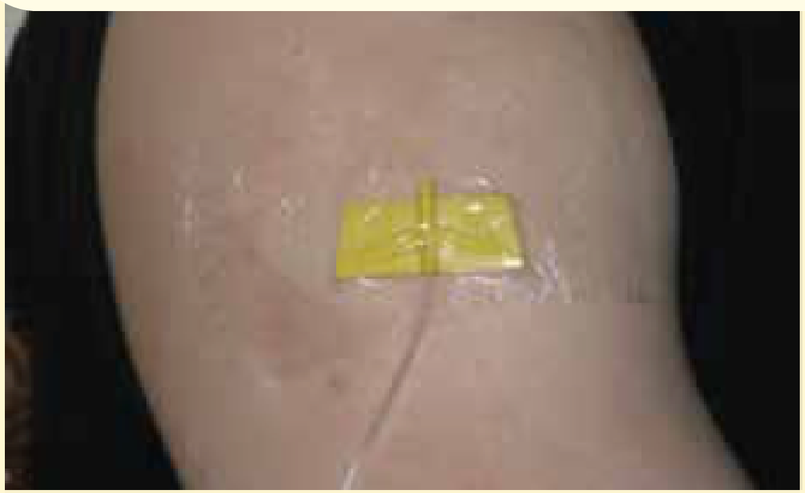
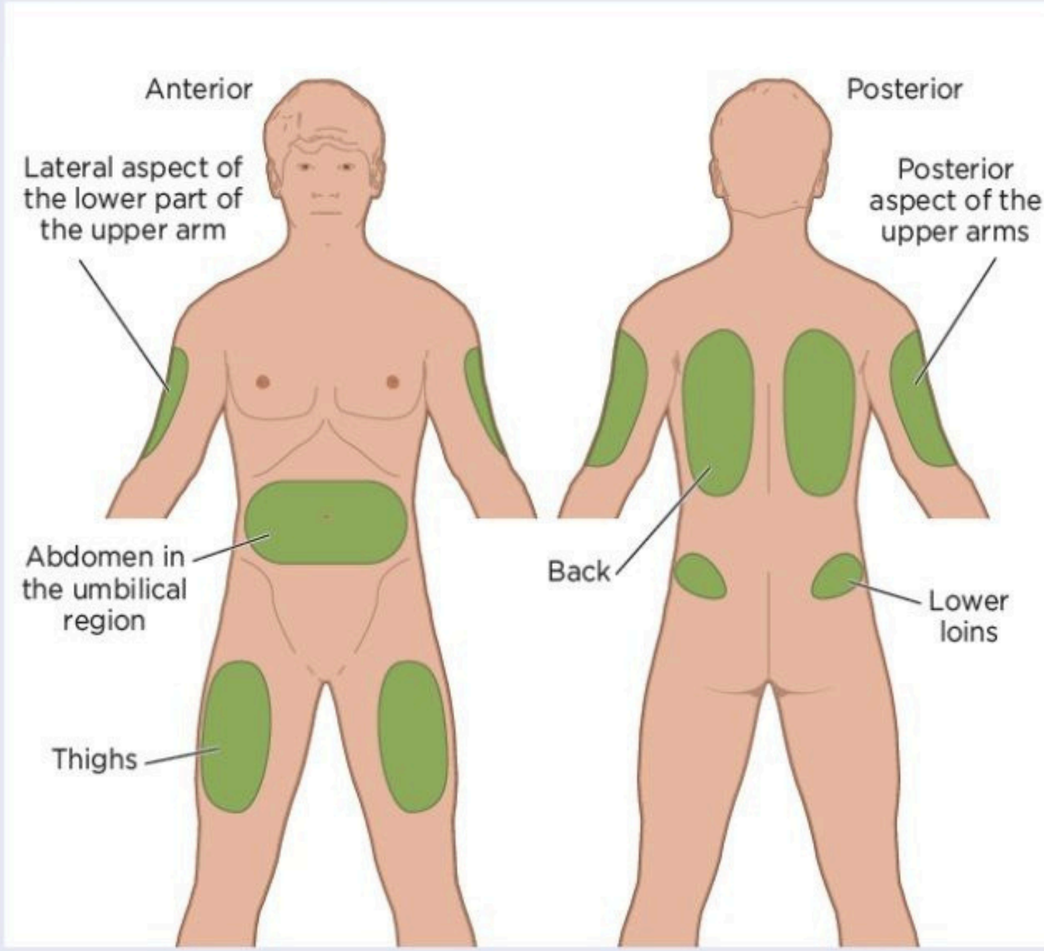
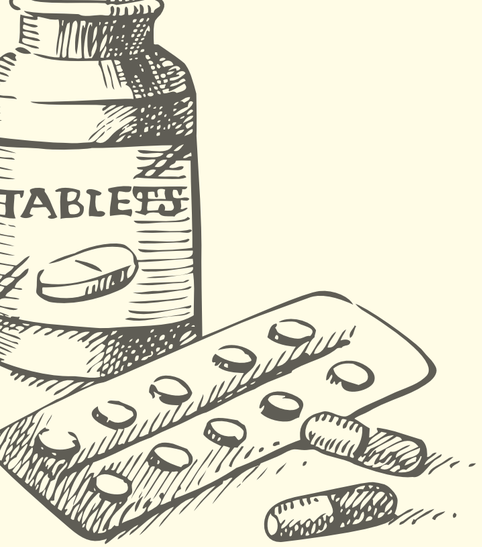


Fig 2. **Subcutaneous injection sites**



Shepherd E (2018) Injection technique 2: administering drugs via the subcutaneous route. Nursing Times [online]; 114: 9, 55-57.

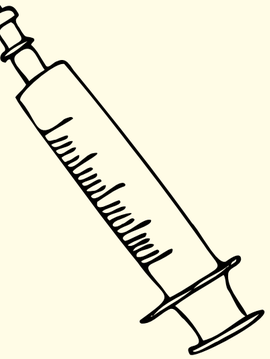
BUCCAL ROUTE



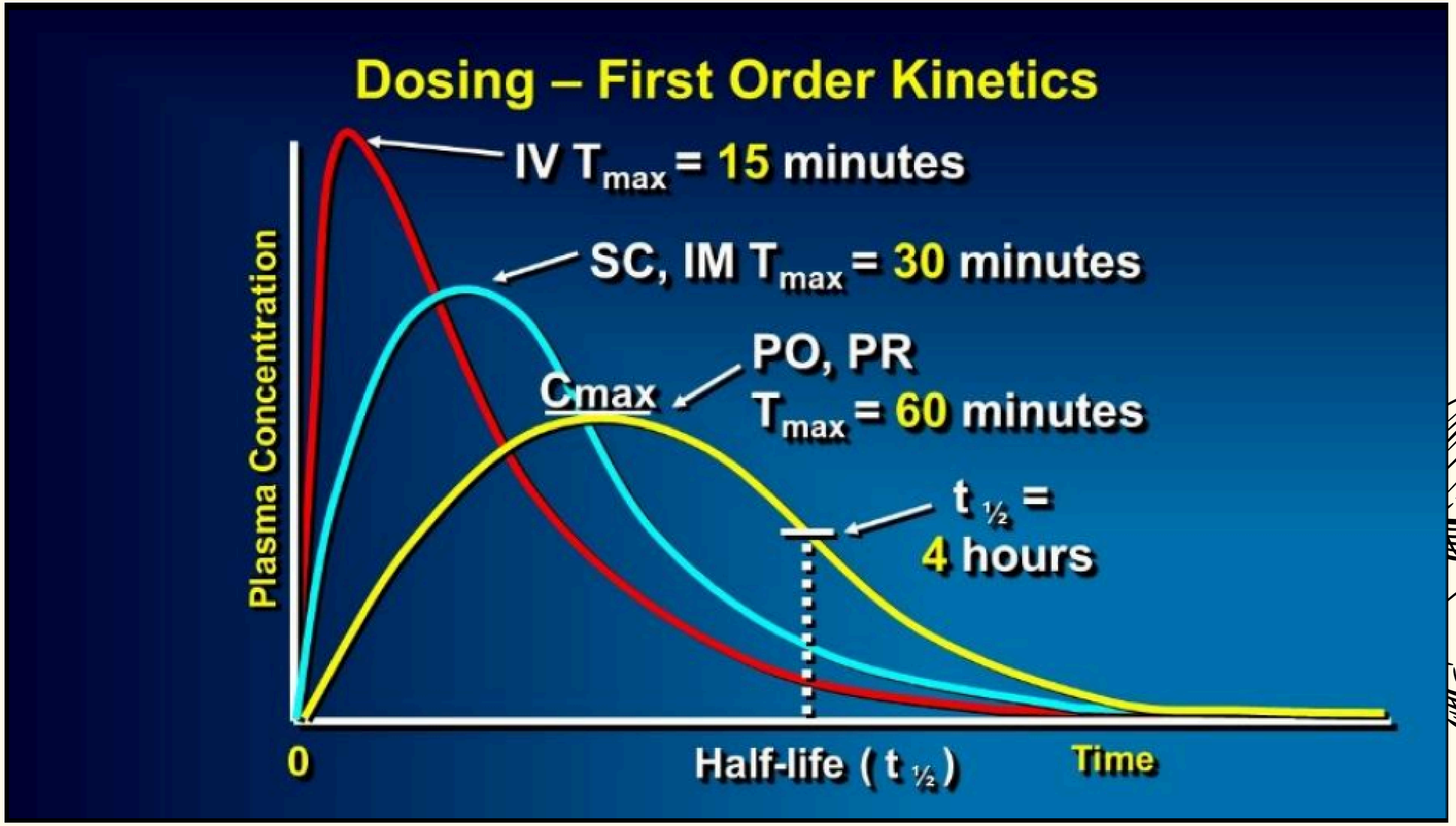
Buccal Medicine Administration

1. **Take the plunger out of a 3mL syringe**
2. **Place the tablet in the syringe**
3. **Draw up 1mL water, 1 mL air**
4. **Shake to dissolve**
5. **Elevate pt at 30 degree angle.**
6. **Using gloved hand, place liquid against buccal mucosa, spread across mucosa**

Never passing your finger through the patient's teeth



Ferris FD. Last Hours of Living. 2022. ISBN: 978-1-945872-55-6. In Ferris FD, Gustin J, Humphrey L (eds). Palliative Care Interdisciplinary Curriculum. PCIC ISBN: 978-0-9884318-1-2.



Iv route : start working at around (Tmax)15 min

SC/IM : Tmax 30minutes

Per Oral/ Buccal: Tmax 60 minutes

ETHICAL SCENARIO IN EOL

Some ethical scenario in EOL

- Withdrawal and witholding life sustaining treatment
- Hydration and nutrition at EOL
- Clinical decision making on CPR
- Medical Futility
- Palliative Sedation and Principle of double effect
- Euthanasia

MEDICAL ETHIC

Medical ethic

Autonomy

obligation to respect the decision making capacity of a person

Beneficience

Obligation to contribute to person's welfare.
Interventions should provide benefit directly to the patient.
it requires positive step to help, not merely avoiding doing harm

Non-malefecient

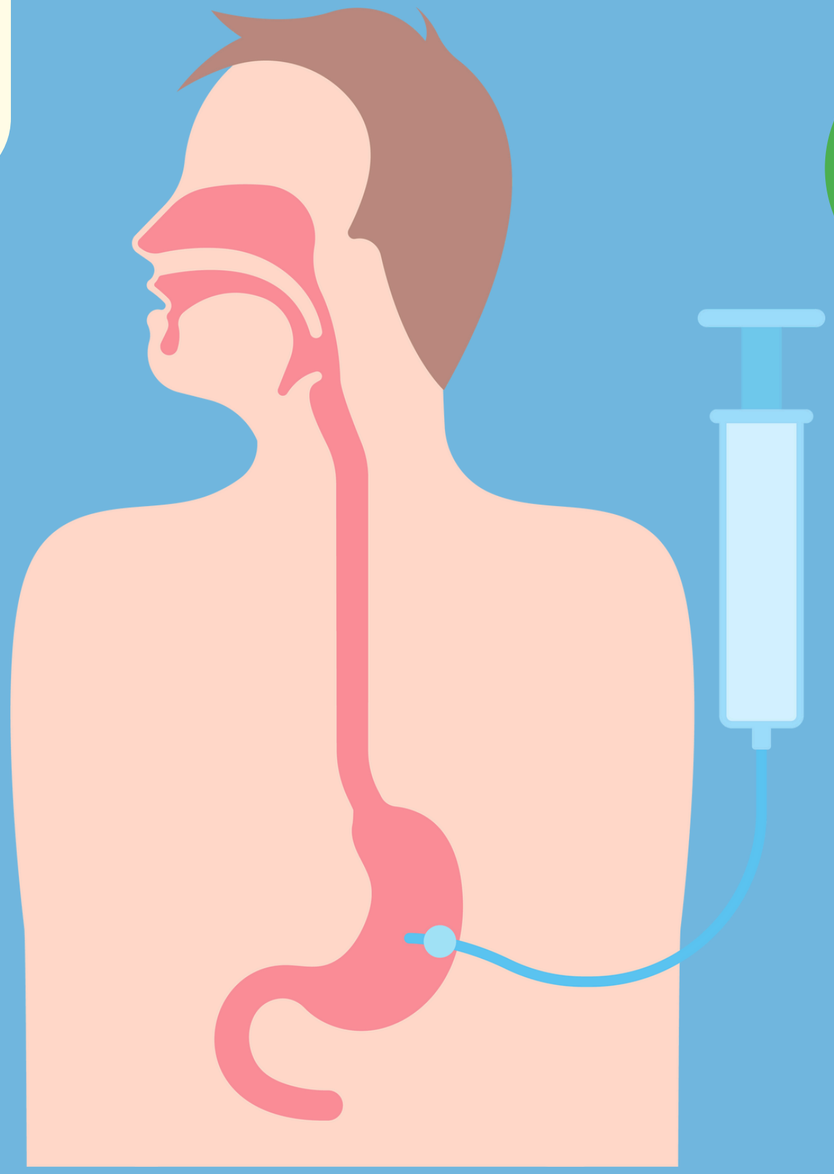
Obligation to not inflict harm on other person.
Harm is to be avoided or minimized.
Underlying tenet of medical professional mission statement (Hippocratic Oath).

Justice

The distribution of health (and health care) in fair and equitable manner. Requires attention to prioritization and rationing

ASSISTED NUTRITION

Clinical Assisted Nutrition and survival



- BENEFIT
  - Head and neck ca with dysphagia and good performance status
  - Cancer with proximal GO obstruction and good performance status and receiving chemo/radiotherapy

- NO SURVIVAL BENEFIT
  - Cancer and non-cancer patient with advanced terminal condition
  - Advanced dementia

Clinically assisted hydration

IV DRIP

- BENEFIT
  - Improve symptoms of delirium, opioid induced neurotoxicity, sedation and myoclonus in pre-terminal phase (Bruera et al, 2005)
  - Thirst, dry mouth, fatigue and other presumed symptoms of dehydration have not show improvement with this alone.

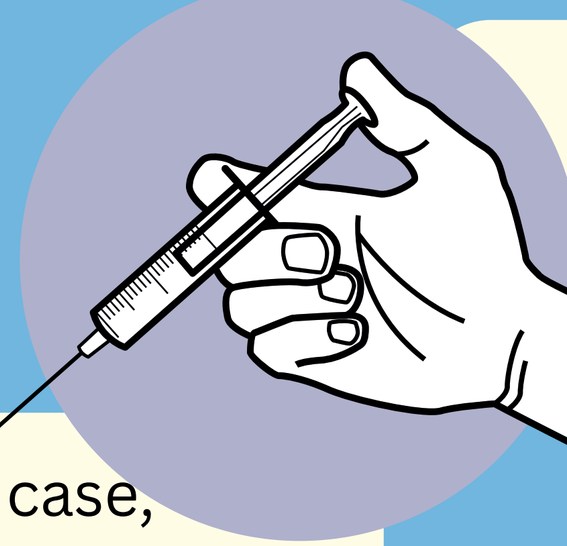
- NEGATIVE EFFECT
  - increase urine, bladder distension, respiratory secretion
  - increase symptoms of fluid retention- edema, pleural effusion (Morita et al, 2005)

Patient passed away after I give Sc injection!

case 1 : A 65 years old gentleman with hepatocellular carcinoma with mets to lung presented with pain at the right hypochondriac region. He was ECOG 4, and have been reported to be sleeping more and having dysphagia since 3 days ago.

- He was given a low dose morphine and titrated with some effect.
- The following day he become confused and restless. This is settled with Haloperidol
- However, after 2 days, the restless was more severe even after given sc Haloperidol. Then he was given sc Midazolam 2.5mg every 30 minutes titrated to a total of 10g before he settled down.
- Pt was calmer after the injection, but 15 minutes later he passes away.

Docrine of Double Effect



“ WHERE AN ACTION, INTENTED TO HAVE A GOOD EFFECT, CAN ACHIEVE THIS EFFECT ONLY AT THE RISK OF PRODUCING A HARMFUL EFFECT, THEN THIS ACTION IS ETHICALLY PERMISSABLE PROVIDED IT SATISFIES THE FOLLOWING CONDITION

- The action is good in itself
- The intention is solely to produce the good effect
- The good effect is not achieved through the bad effect
- there is sufficient reason to permit the bad effect

However, In this case, patient was already showing signs of dying

- the medication haven’t taken effect (Tmax at 30 minutes)
- and if the medication have taken effect, the dose that we use are not lethal (still a safe dose)

Remember!

You may feel guilty, anxious or panicky if pt passed away right after you gave them the sc injection. This can be a traumatizing experience espsecially to newer member of palliative unit.

What's important to recognize is, the patient died because of their disease, not because of the medication that we use to control their symptoms

Psychospiritual care at EOL

SAYING GOODBYE

4 thing to say before a loved one dies (Ira Byock)

1. I love you
2. Forgive me
3. I forgive you
4. Thank you

COMMUNICATING WITH THE UNCONSCIOUS PATIENT

1. Create familiar environment
2. Assume patient hear everything
3. Include pt in conversation- reassure pt of presence, safety
4. Touch
5. Play music that pt enjoys/ read Quran/ bibble if pt have enjoyed that before.

Giving permission to die

- **Pt may be waiting for family to accept that he/she is dying**

May need to hear from each family member

- **Family need guidance on how to :**

  - saying the 4 phase
  - state their preparedness for pt to die
  - give reassurance that the family will still be fine even after her passing.
  - giving permission for pt to go
  - say goodbye

Conclusion

1. It is important to know your patient , their diagnosis and where are there in their disease progression
2. Knowledge empowerment patient and family on how to plan and manage their life around the disease. Provide the knowledge on what to expect, the changes that they will see, and the resources that you can provide or and other team can provide.
3. Withdrawing treatment does not mean withdrawing care. Help patient manage their their symptoms in every phase of their journey as much as we can.
4. Sometimes, some family member may reacted negatively to your suggestion. Remember, THIS IS NOT ABOUT YOU. Be professional, still treat patient with compassion until the end of the journey.

thank you

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