End of Life Care - EOLC

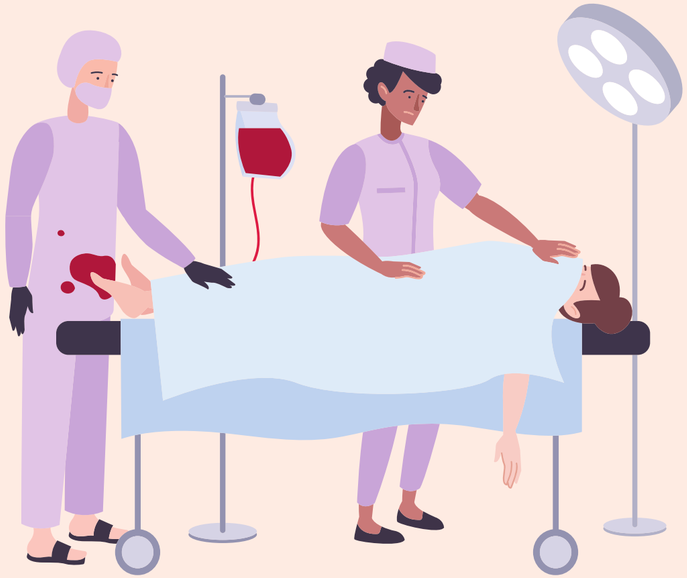
For FLW

LEARNING OBJECTIVES

- Enumerate the signs of terminal stage/ dying.
- Enumerate common complaints [death rattle, agitation and breathlessness]
- Describe a good death
- Describe the stages of bereavement
- Differentiate between normal and pathological grief
- Describe the process of death registration and obtaining death certificate

REFLECTION

- Have you ever thought about your own death?
- What kind of death would you like to have?
- What kind of death would you consider as a Good Death?



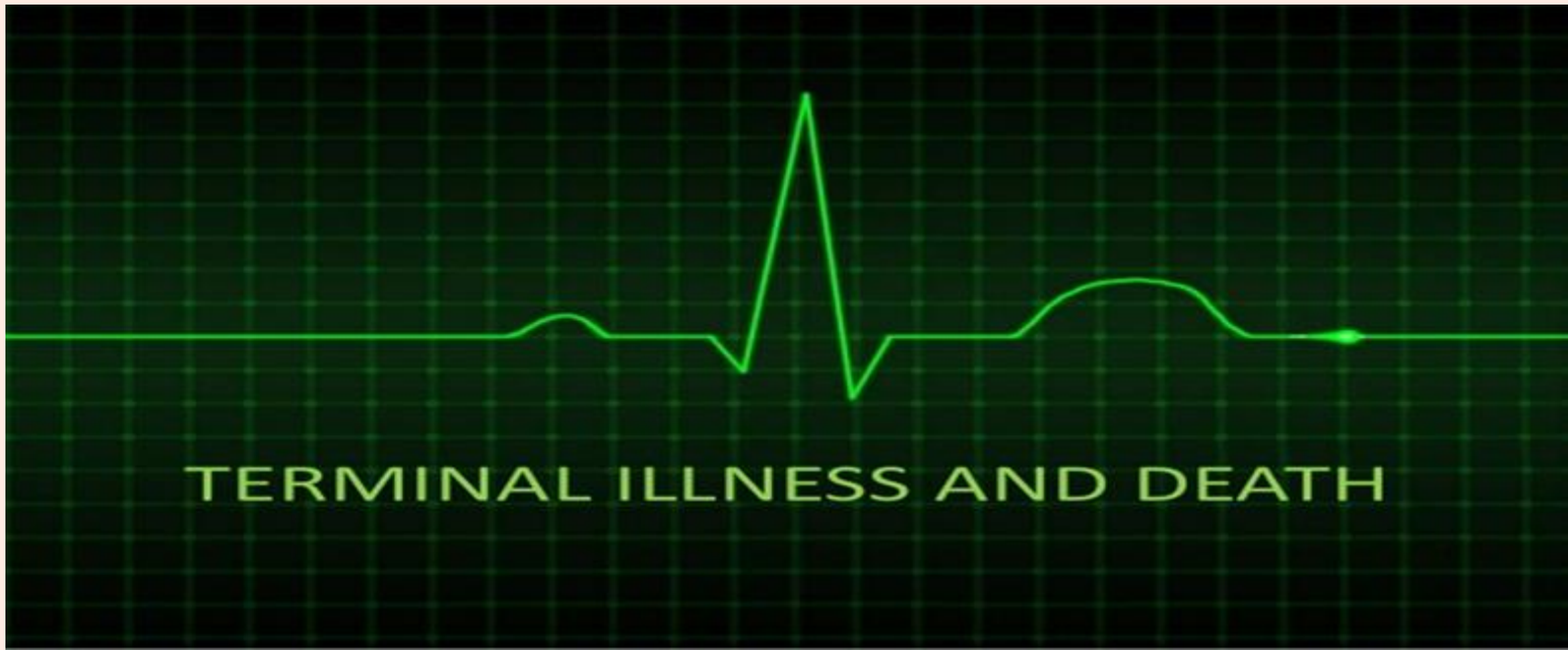
WHAT IS EOLC?

End of Life Care is the way of caring for a terminally ill patient that **shifts attention to symptom control, comfort, dignity, quality of life and quality of dying** instead of trying to cure or increase the life.

WHAT DO WE UNDERSTAND?

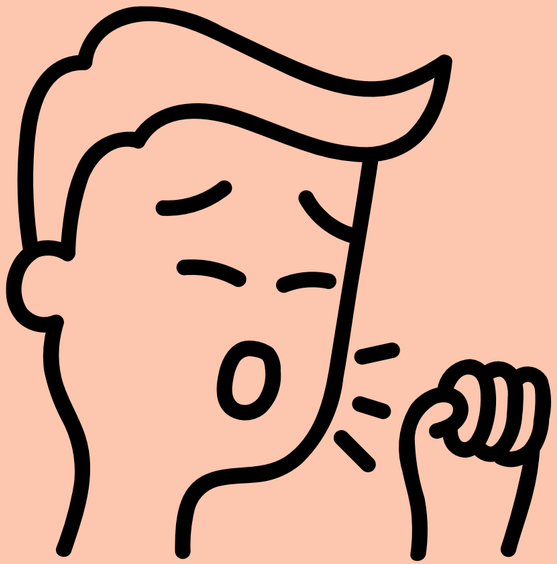
Terminal Illness

- is from which recovery can not be expected with the available treatment
- death is considered to be unavoidable in the foreseeable future (usually 6 months to 1 year)

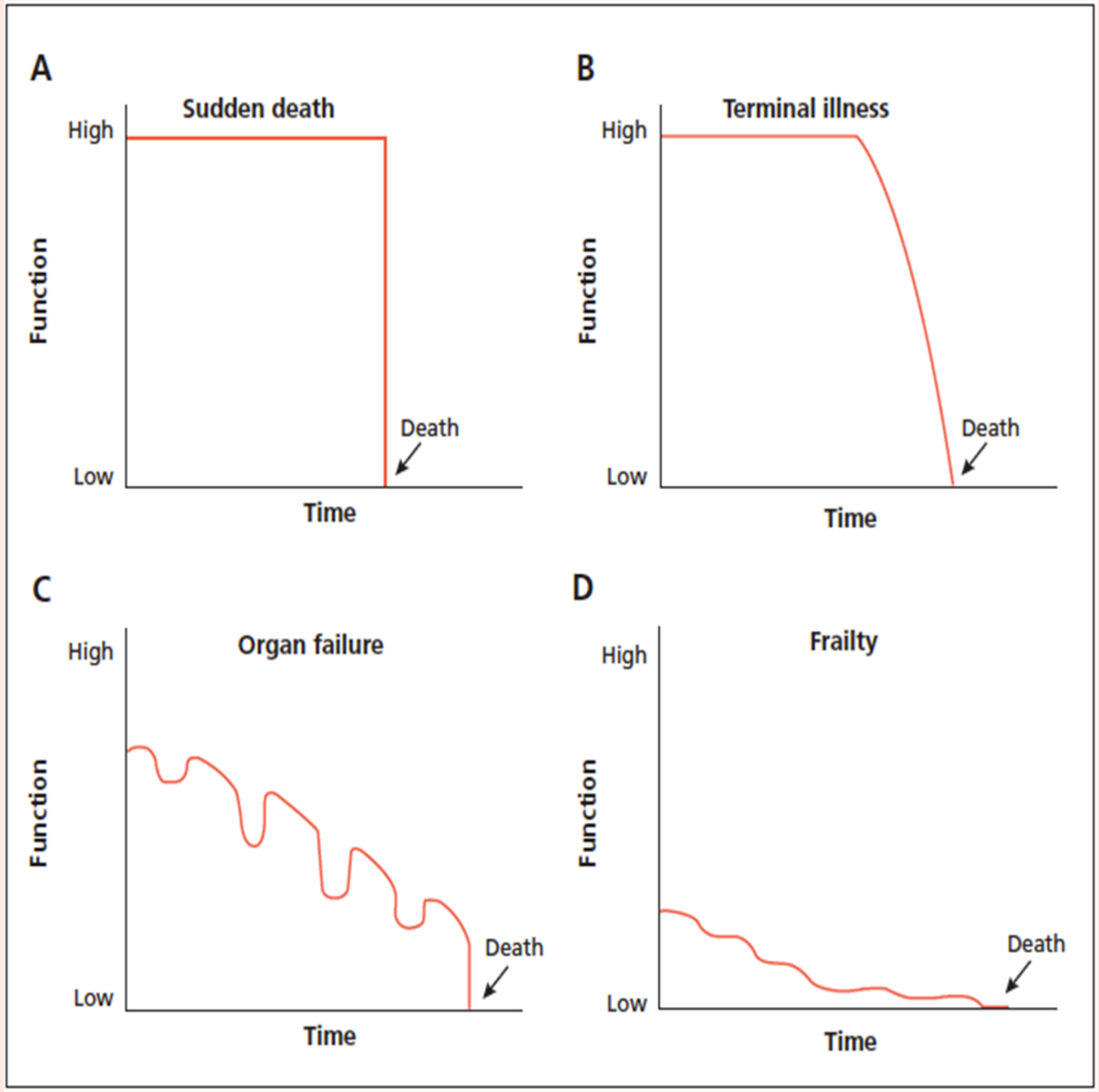


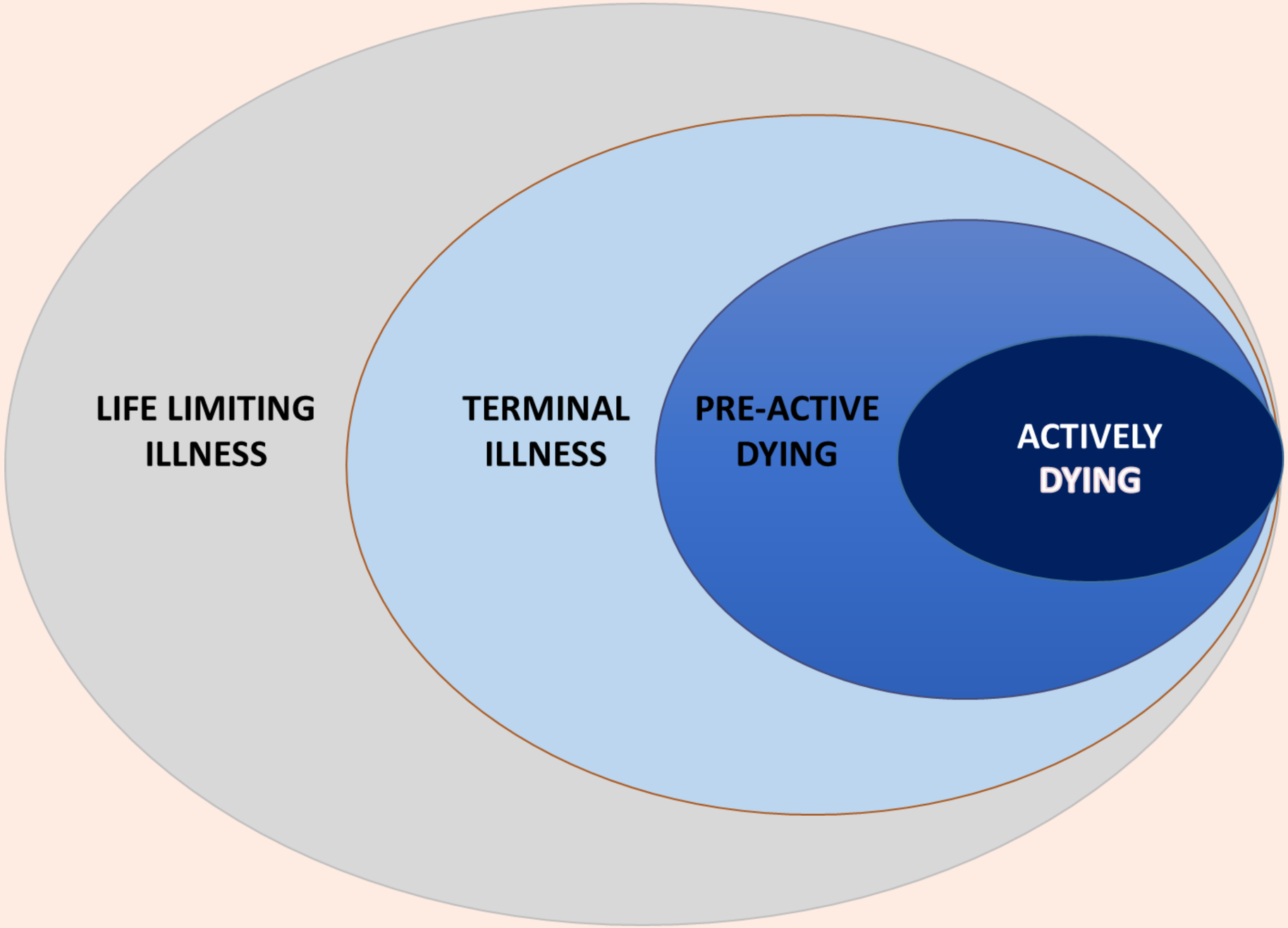
HOW TO RECOGNIZE TERMINAL ILLNESS

- **Withdrawal** from social activities
- More sleepy**, lethargic, food intake** decreases
- **Wound** no longer recovers
- **Confusion** and restlessness
- **Swollen** legs and hands
- Clearing emotional issues
- Period can go on for 2 months but usually less than 1 month



HOW DO WE DIE: FOUR ROADS TO DEATH




LIFE LIMITING ILLNESS
TERMINAL ILLNESS
PRE-ACTIVE DYING
ACTIVELY DYING

ACTIVE DYING

- Change in breathing (jerky, noisy, rattling at back of throat, very slow, gasping)
- Confusion, restlessness, agitation, seeing things/people who are not there and intermittent or complete loss of consciousness
- Increasing pain, even on movement
- Loss of bladder and bowel control
- Cold hands and feet with mottled skin
- Dark, small quantity urine
- BP drops 20-30 mm below usual or becomes unrecordable

GOALS OF EOLC

- Explaining and communicating with caregivers, so that they are mentally prepared
- Making the patient as comfortable as possible.
- Giving ‘individualised care’

EXPLAINING AND COMMUNICATING WITH CAREGIVERS

- Find out **how much they understand.** Find out if they wish to know more about the prognosis and discuss accordingly. **Address their fears**

- A **person important to them should be present** during the discussion.

- **Provide contact information** (ambulance, your contact, nearest doctor, hospital, etc.) Find out if they have **any religious, cultural, social or spiritual needs.** Explain the **uncertainty** about the exact the **time of death**

- **Document** the discussion along with the names of the persons discussed with. **Discuss the case with the doctor** concerned and document it

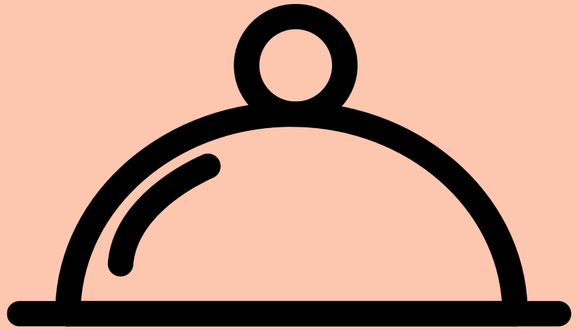
GIVE ‘INDIVIDUALISED CARE’

- Assess level of consciousness
- Find out the patient’s wishes
- Record and document preferred place of care (home, hospital, etc.)
- Find out the wishes of the caregivers
- Remember…the wishes and plans may change

FOOD AND FLUIDS

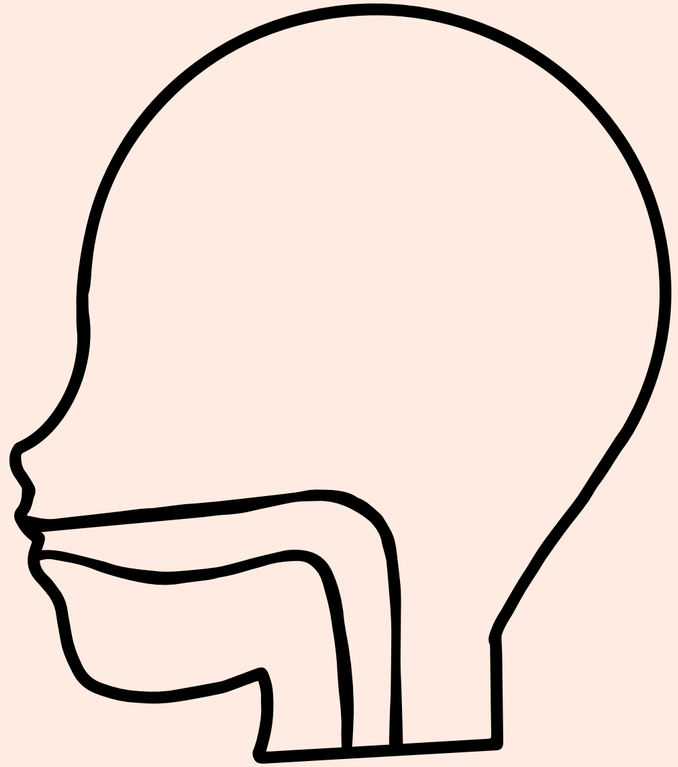
Remember : Body is shutting down and intake is going down accordingly

- **Total fluid requirement**
  - About 1 litre per day
  - If needed can be given subcutaneously
- **No Ryle's tube**
  - Discomfort
  - Does not reduce risk of aspiration
- **No IV fluids**
  - Risk of pulmonary edema
- **Hand feeding or with spoon**
  - Aspiration risk is manageable



IF SWALLOWING IS DIFFICULT

- Feeding with a spoon is helpful
- Ensure that the first sip has been swallowed before the next sip if given.
- Discuss risk of aspiration
- Encourage caregivers to give lip and mouth care
- What the patient can be given depends on the level of consciousness, ability to swallow, level of thirst, need for medicines



ADVERSE EFFECTS OF IV FLUIDS

- Difficult at home
- Expensive
- Needs supervision
- Infection can occur
- Fluid can collect in the lungs

DO A REGULAR REVIEW

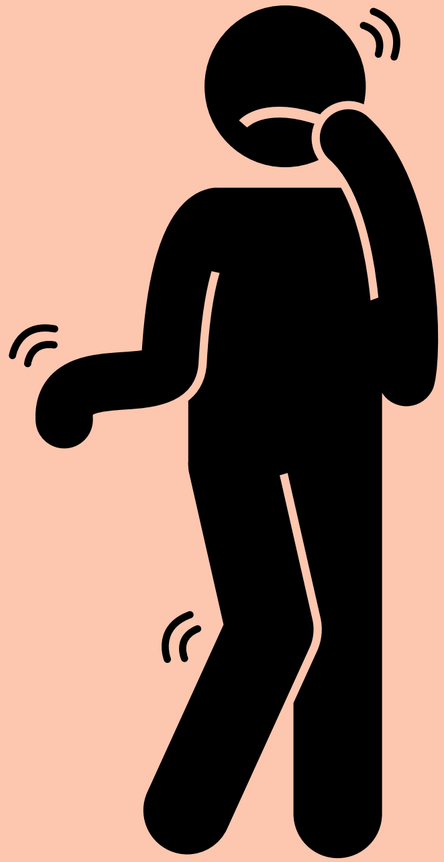
- Check with doctor about which ‘non-important’ medicines can be stopped and which to continue.
- The doctor will decide on the best way to give medicines
  - Intramuscular and intra venous routes are avoided
  - Subcutaneous injections can be used

SYMPTOM CONTROL

- **Pain**
  - Check with doctor for medication
- **Not eating,** Check with doctor for nasogastric feeding
- **Incontinence** Teach family to clean patient, catheterise after teleconsult with doctor
- **Breathlessness**
  - Fan the face, Stroking on the back
  - Medications like morphine, alprazolam
  - No oxygen

ANXIETY, RESTLESSNESS AND CONFUSION

- Look for causes like pain
- Ask the doctor for medication



DEATH RATTLE

- Due to collected secretions at the back of the throat when patient is too weak to swallow them. They do not cause discomfort to the patient but relatives may be worried that he is choking or in pain. Explain to caregivers that it does not cause distress to the patient

- Try non-drug measures

    - Position the patient in recovery position. Remove the secretion from angle of mouth using finger wrapped in a gauze piece by ‘hooking’ the finger and ‘swiping’

- Ask the doctor for medication

FITS

- Prevent the patient from self-harm.
- Do not force any object like a spoon into the mouth.
- If possible, give intravenous, subcutaneous or intramuscular midazolam or any other drug suggested by the doctor
- Continue anti-epileptics as prescribed

SEVERE BLEEDING

- Plan for this possibility and discuss with family in advance
- Apply firm and steady pressure where possible using dark towels or bedsheets
- Sedate the patient quickly with intravenous, subcutaneous or intramuscular midazolam or any other drug suggested by the doctor

SUPPORTING THE FAMILY

- The family is suffering as much or even more
- Address religious, social and spiritual needs
- Arrange extra help, including help from a doctor

PREPARING FOR THE END

- **Stops breathing and/or heart beat stops** –don't start oxygen

- Listen for heartbeat, if a stethoscope if present
  - Listen for heart sounds for at least 2 minutes
  - Listen for breath sounds for at least 3 minutes

CONFIRMING DEATH AT HOME

- Introduce yourself: The family can stay inside or wait outside as they wish
- Wash hands
- Confirm identity
- Watch for signs of life: movement, breathing, twitching
- Response: voice, pain, pupils
- Feel for pulse at neck (carotid), heart beat with stethoscope
- Wash hands

DOCUMENTATION

- Documentation of your assessment with date, time, name, and position.
- A document that a family member (name and relation) has been informed about the death.
- Inform the CHO, doctor/RMP/village Panchayat/BDO

ONLY A REGISTERED MEDICAL DOCTOR CAN CERTIFY DEATH

BEREAVEMENT SUPPORT

- After death: bereavement visit
- Collect back unused Medicines
- Family needs support
- Address religious, social and spiritual needs
- Normal grief: up to 6 months
- Complicated grief: depression: may need medical help

ROLE OF ASHA

- Identification of terminally ill patients
- Inform to MPW
- Basic care of dying
- Home visits
- Bereavement care and identification of mental health consequences in family.

ROLE OF MPW

- Identification of terminally ill patients
- Reporting to CHO
- Home visits with basic care of dying
- Education of family about basic technique in care
- Provision of essential drugs
- Retrieval of unused opioids after death

KEY MESSAGES

- Terminal illness can be identified.
- Focus has to shift to symptom control, comfort and quality of life for the patient and family.
- Active dying phase must be recognized and family must be prepared for patient’s death.
- Family support begins before death and continues afterwards as well: Bereavement

EVALUATION
(IDENTIFY THE INCORRECT OPTION)

1. Terminal illness

a. Can only be identified after death

b. Can arise during any chronic, life limiting condition

c. Usually lasts less than a year

2. If a terminally ill patient stops eating and drinking

a. Attempt hand feeding

b. Can start fluids subcutaneously

c. Pass Ryle's tube

3. Discussion with patient and family

a. Should be avoided as far as possible

b. Place of care should be identified: whether home, hospice or hospital

c. Bereavement calls up-to 1 year after the death of the patient

ANSWERS

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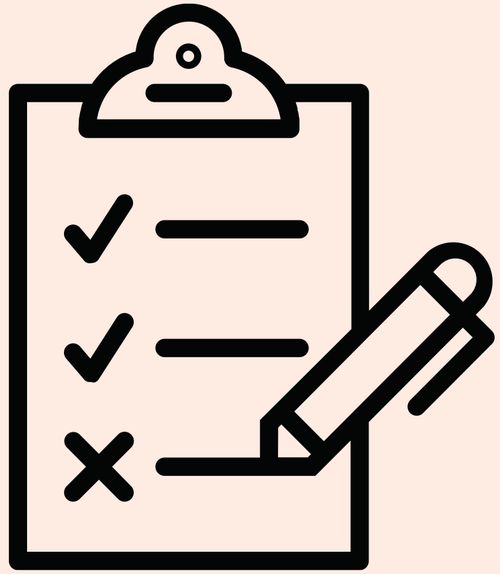

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‘At the end of life we will not be judged by how many diplomas we have received, how much money we have made, how many great things we have done. We will be judged by "I was hungry, and you gave me something to eat, I was naked and you clothed me. I was homeless, and you took me in”.

Mother Teresa

Thank You