# INTRODUCTION TO PALLIATIVE CARE

BY

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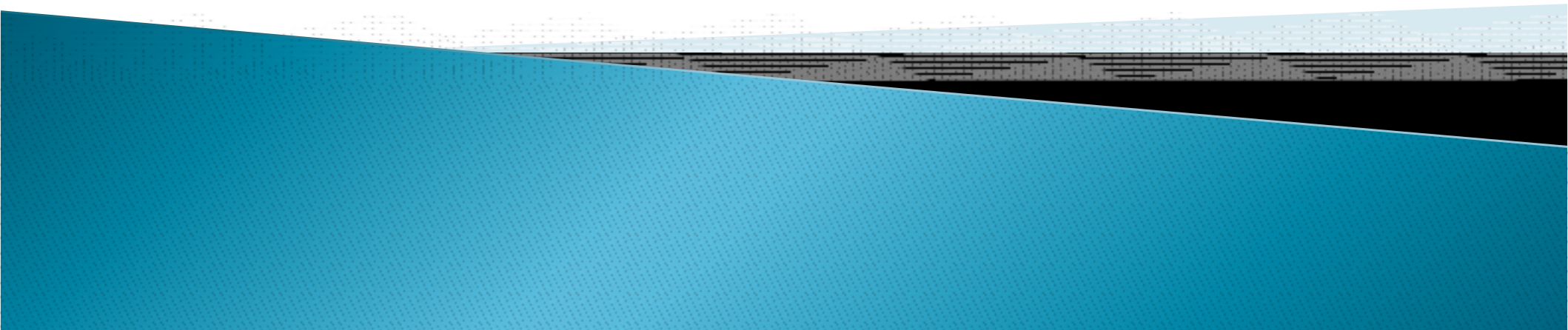


# HISTORY AND OVERVIEW OF PALLIATIVE CARE

The original Hospice go back to Fabiola, a Roman matron who opened her home for the poor, travellers, hungry, thirst and the sick

At that time the word Hospes(Greek) meant both host and guest, and the word Hospitium(Latin) meant the place where hospitality was given

# Cont'

Today hospice is a philosophy of care. Hospice is not a building but;

- A philosophy of care that believes that pts have rights and are able to help in caring for themselves. Hospice recognizes the rights of pts and their families in decision making
- Hospice has a variety of team members w/c may include nurses, Drs, social workers, community workers, physiotherapists & occupational therapists. This team works together as a family

# Aims of Hospice

- It aims at putting life in the remaining days rather than days into the remaining life
- It relieves pain and other symptoms
- It aims at giving the best possible quality of care for the pts and their family members
- It aims at providing end of life care i.e. helping pts to die in peace & with dignity
- It aims at carrying out bereavement support to the bereaved family(ies)

# History of Hospice in Africa

Hospice has been established in the following African countries;

1. Zimbabwe for over 20yrs
2. South Africa for more than 20yrs
3. Kenya-Nairobi since 1990
4. Hospice-Africa Uganda since 1993

HAU introduced palliative care in Uganda in 1993 Sept. by Dr Anne Merriman. She was the 1st person to introduce oral liquid morphine in Uganda. This allowed pts to die free of pain and with dignity

# Managerial services of Hospice

This cares for pts with HIV/AIDs or and cancer. This is normally done mainly in their homes. Pts with HIV/ AIDs are care for during acute painful conditions. Such conditions are;

- Creptococcal meningitis
- Herpezoster & other OIs especially during their end of life phase
- Cancer pts & their families are looked at after the Dx, death & bereavement phases happen
- Pts are not charged for the services offered. It works as a team w/c comprises of all H/workers & community workers

# Cont’

**Palliative care:** The word “palliative” comes from the Latin word “pall” meaning a blanket or cover. This denotes the all-embracing (holistic) and comforting aspects of palliative care.

The word was used for the first time in exchange for the word Hospice, in Canada in the 1970’s. The people of Canada had used the word Hospice to mean a house where people who had no other supports were sent to die

# Cont'

Similarly in Singapore, there was a feeling that Hospice was substandard care given to the abandoned coming to death.

Thus in order for Hospice care to be recognized as anew specialty, the name palliative medicine was given to the specialty and the approach is called palliative care

# WHO definition of palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life threatening illness, thru the prevention & relief of suffering by means of early identification & impeccable assessment & treatment of pain & other problems, psychosocial and spiritual.

# Goals

- To maximize the quality of life for the people living with HIV/AIDS and or cancer as well as their family members
- To minimize suffering through provision of a comprehensive health package

# Purpose of palliative care

It is to meet the physical, psychological, social and spiritual needs of the individuals and their families facing life threatening illness while remaining sensitive to their cultures and beliefs

# Objectives of Palliative care

- Provides relief from pain & other distressing symptoms
- Affirms life & regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates the psychosocial & spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement

# Cont’

- Uses a team approach to address the needs of the patient & their families, including bereavement, counseling & if indicated
- Will enhance quality of life & may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, & includes those investigations to better understand & manage distressing clinical complications

# Cont’

**Dame Cicely said;**

- You matter because you are you
- You matter up to the last moment of your life
- And we will do all that we can to help you to live until you die

# Principles of palliative care

There are majorly 4 principles of palliative care;

1. Management of pain and other related symptoms. This involves the use of both modern and local interventions i.e. non pharmacological and pharmacological measures. Pain can be spiritual, social, physical, emotional and psychological. Therefore being free of pain is a human basic right.

# Cont'

2. Psychosocial support. This involves psychological and social aspects i.e. a counselor, patient, and family members need to work together for a common goal
3. Team work and partnership i.e. no single health worker can adequately address a patient's problem or needs alone
4. Appropriate use of medical ethics w/c are;

- Do good
- Do no harm
- Consider patient's rights to decision making (respect for the patient)
- Maintain fairness

Essential components of palliative care

- Pain and symptom contol
- Support care; this includes all components of hillistic care

# Core members of palliative care

These include;

1. Health professionals e.g. nurses, Drs, C/os etc
2. Supportive staff e.g. social workers, occupational therapists, physiotherapists, counselors, auxillary staffs etc
3. Community members such as volunteers
4. Community health workers, traditional healers, spiritual care supporters etc
5. Family members e.g. all relatives, friends etc

Note; All the above have an important role to play in provision of palliative services to patients

# Holistic care

This is the care of the whole person incorporating physical, psychological, social & spiritual aspects. Holistic care approach understands the pt as whole being in the context of his/her environment

The environment is made up of family members, friends, cultural leaders, spiritual leaders, traditional healers etc

It also understands the pt's specific needs and responds to them individually. It uses a multidisciplinary team to achieve total care for the patient and family

# THE INTRODUCTION OF PALLIATIVE CARE IN UGANDA

Hospice Uganda was established in Kampala September 27th 1993. The concepts of hospice and palliative care are well accepted in Uganda but the delivery of services have been severely contained by limited resources

# CHALLENGES AND ISSUES

**Back ground:** More than 50million people die thru out the world each year. The majority of these deaths are in developing countries. Even where advanced therapies are available, length of life may be reduced for those with HIV. In addition advanced HIV illness is associated with severe pain

People living with HIV in developing countries can there4 expect a shorter life span, & their death is likely to be unnecessarily painful & undiagnosed

Care for the dying is not new & different cultures have different approaches to help these people at the end of their lives

# Cont'

Palliative care is based on a model developed in response to the needs of cancer patients. It aims to make death a pain free process which includes support, comfort & relief of symptoms making it possible for people to die with dignity

For people with HIV, palliative care is an essential part of treatment, not only as death approaches but also thru the treatment of potentially fatal symptoms of opportunistic infections

# Cont’

Such treatment, while not curative, never the less prolongs life for considerable periods of time & restores quality of life

The HIV epidemic has led to increased efforts to provide care & support for people in their homes. While this has been a great step towards the care that people need, many home care projects are unable to provide the pain relief & treatment of symptoms that are needed to prolong life & ease dying and death

# Cont’

Huge investment is needed to ensure that when advanced treatment is no longer effective, or when it is inaccessible for any reason, people can have access to symptomatic treatment and pain relief.

The obstacles are political, financial & lack of understanding & training in the palliative care approach

As with other modes of health care, HIV brings its own particular challenges concept and implementation of palliative care

# THE ROLE OF PALLIATIVE CARE NURSE SPECIALIST IN UGANDA

Background: Palliative care is not a priority in developing countries. Hospice Africa-Uganda (HAU), where nurses complete a course in clinical palliative care is considered a model for other African countries

AIM: To explore the role of palliative care nurse specialist (PCNS) in Uganda.

- The role of palliative care nurse specialist is multifaceted beyond prescribing drugs, their role is to deliver holistic care
- They encounter numerous challenges in their work but they also have the possibility to improve the quality of the patients' life

# Cont'

The WHO has advised Uganda to ↑se access to palliative care services for patients with life threatening infections including HIV/AIDS. Palliative care is a specialized approach that involves providing patients with life threatening conditions, relief from pain and stressing symptoms. Ideally palliative care services should be provided from the time of diagnosis for the life threatening illness, adapting to ↑sed needs of cancer patients & their families

# Cont’

Palliative therapy was introduced in Uganda in 1993 by Dr. Anne Merriman, the founder of hospice Africa.

When you go to a health centre, the health workers only focus on the disease, but there are other social, or even spiritual issues that affect the patient, which needs to be addressed

# ETHICAL PRINCIPLES

Ethical principles in palliative care centre around the following terms:

1. **Autonomy (Respect for the patient)**

It includes differences to and acknowledgement of the pts rights in making decisions, treating the pt with compassion & dignity, maintaining confidentiality & respect for the pt, privacy, avoiding misrepresentation, deceptive & non disclosure & keeping promises

# Cont'

Fundamental to "pts autonomy to make is the requirement for informed consent" besides fulfilling legal requirement, the purpose of informed consent is to pt self determination & enhance pts wellbeing. Pts autonomy however is not absolute if the person is incapable of or incapacitated in making decision, if the decision can harm others or impose unfair claims on society's resources. And there are exceptions as well to informed consent e. g.

- emergencies
- lack of decision making capacity &
- therapeutic privilege

# cont’

2. **Non maleficience (Do no harm)**

This is more strength than benefit. It forbids the use of ineffective therapies, or prescribing a treatment in which the risk outweigh the benefits, or even acting selfishly or maliciously

# Cont’

3. **Beneficience (To do good);** means to take positive action to benefit the pt or help others such as advocating for less fortunate members of the society. The problem is acting in the pts best interest but who makes the determination of the pts interests

There may be disagreement over what is best for a pt & quality of life. Judgments by others may not reflect the patients

# Cont’

Moreover, the old paternalistic approach in which the Dr. always knows best is no longer sufficient to override the pts wishes. If pt lacks decision making capacity, the Dr. should be guided by pts best interests and not by pts autonomy especially when the pt requests interventions that may be harmful than beneficial or when the pt requests interventions whose benefits can only be assessed by patients

# Cont’

4. **Allocate resources justly or fairly (Just);** refers to the fact that Drs should allocate resources wisely based on benefits & risks to pts rather than costs. That people who are situated equally should be treated equally & that rationing eye & vision should be avoided because its inconsistent.

# Cont’

Drs have limited time & resources & there4 should ration, time & resources according to pts needs & probability to & degree of benefit. To spend an inordinate amt of time on one pt while others are waiting may not be an appropriate use of Drs time or for a pt to request or demand that the Dr conduct additional tests beyond necessary for the pts condition may not be a wise use of resources

# PHYSICIAN ASSISTED SUICIDE (PAS)

**PAS:** The voluntary termination of ones own life by administration of a lethal substance with direct assistance or indirect assistance of a physician.

Physician assisted suicide is the practice of providing a competent patient with a prescription for medication to use with the primary intention of ending his or her own life

# EUTHANASIA

According to Mediacom's medical dictionary;
Euthanasia is;

1. “A quietly painless death” or
2. “The intentional putting to death of a person with an incurable or painful disease intended as an act of mercy”

# EUTHANASIA IN HISTORY

The English medical word “Euthanasia” comes from the Greek word Eu meaning “good” and thanatos meaning “death”

Euthanasia is mentioned in the Hippocratic oath. The oath states “ to please no one will I prescribe a deadly drug, nor give advice which may cause his death”

Even so the ancient Greeks & Romans were not strong advocates of preserving life at any cost, and were tolerant of suicide when no relief could be offered to the dying

# ENGLISH COMMON LAW

Suicide was a criminal act from the 1300s until the middle of the last century; this included assisting others to end their lives.

Physician assisted suicide has its proponents and its opponents

Among the opponents are some physicians who believe it violets the fundamental tenet of medicine and believe that Drs should not assist in suicides because to do so is incompatible with the Drs role as a healer

# Cont’

**In majority of countries Euthanasia is against law. Although few countries regard it as legal. There are two main classifications of Euthanasia;**

a) **Voluntary Euthanasia.** This is Euthanasia conducted with consent. Since 2009, voluntary Euthanasia has been considered legal in belgium, Luxembourg, Netherlands, Switzlandand the states of Horegon (USA) and Washington

# Cont'

b) **Involuntary Euthanasia.** Is conducted without consent. The decision is made by another person because the patient is incapable to doing so himself or herself

There are two procedual classification of euthanasia

1) **Passive Euthanasia**: Is when life sustaining treatments are with held. The definition of Passive Euthanasia is often not clear e.g. if a Dr prescribes ↑sing doses of opioid analgesia (strong pain killer) which may eventually be toxic for the pt, some may argue whether passive euthanasia is taking place. In most cases, Dr's measures is seen as a passive one. Many claim that the term is wrong b'se euthanasia has not taken place, bse there is no intention to take away life

# Cont’

2) **Active Euthanasia:** or lethal substance or forces are used to end a pts life. Active euthanasia includes life ending actions conducted by the pt or some body else.

Active euthanasia is a much more controversial subject than passive euthanasia. Individuals are torn by religious, moral, ethical & compassionate arguments surrounding the issue. Euthanasia has been a controversial and emotive topic for long time

# Cont’

Active euthanasia. Is a mode of ending life in the intend to cause the pts death in one single act (also called mercy killing)

Passive euthanasia. Is a mode of ending life in which a physician is given an option not to prescribe futile treatments for the hopelessly ill patients

# Options for terminal patients or those with intractable suffering and pain

Patients with a terminal or serious & progressive illness in most developing countries have several options including;

1. Palliative care. The WHO defines palliative care as an approach that improves the quality of life of pts & their families facing problems associated with life threatening illness thru the prevention & relief of suffering by means of early identification & impeccable assessment & Rx of pains & other problems; physical, psychological and spiritual

# Cont'

2. Refusing treatment. In many other countries, a pt can refuse Rx that is recommended by a Dr or some other health professional as long as they have been properly informed & with sound mind

According to the department of health, nobody can give consent on behalf of an incompetent adult e.g. one in coma. Never the less Drs take into a/c the best interests of the pt when deciding on Rx options. A pt's best interests are based on;

- What the pt wanted when he/she was competent
- The pt's general state of health
- The pt spiritual & religious welfare

# EMERGENCE CARE PRINCIPLES

A palliative care emergency is any change in the pts that requires urgent & immediate intervention. Assessment must be prompt & complete if good results are to be achieved. The following should be considered during the Mgt of palliative care emergency;

- Nature of the emergency
- General condition of the patient

# Cont’

- Stage of the disease and prognosis
- Availability of possible treatment
- The likely effectiveness and toxicity of available treatments
- The patient wishes
- The carer’s wishes

# TYPES OF PALLIATIVE CARE EMERGENCIES

- Bone fractures
- Chocking
- Haemorrhage
- Hypercalcaemia
- Seizures
- Severe uncontrolled pain
- Spinal cord compression
- Stridor
- Superior venacava obstruction (SVCO)

# Assessment of the emergency

- What is the problem. Its important to make a proper diagnosis
- Can the problem be reversed
- What effect will reversal of the problem have on the patient's overall condition
- Can active intervention maintain or improve the patient's quality of life
- If the Rx option in mind is available & affordable
- What the patient wishes
- What is the carer's wishes

# MGT OF PALLIATIVE CARE EMERGENCIES

## BONE FRACTURES

Bone fractures can occur with no or minimal trauma especially to weight bearing bones such as the femur and the vertebra

Causes;

- Fractures are common when there is a wide spread bone metastases in cancer such as lung cancer, breast cancer, renal cancer and myeloma
- Bone fractures may also be due to osteoporosis

# Cont’

**Signs/symptoms**

- Severe pain around the site
- Deformed limb
- Pain on movement
- Bone grafting
- Inability to use the limb
- Patient may go into acute confused state

# Assessment and management

- Analgesia & efforts to immobilize the site of fracture composed first remedial steps
- immobilize the limb where possible. This may mean applying a splint or POP cast, though if the pt is fit enough it may be possible surgically to stabilize the fracture
- Radiotherapy can be given and even a single fractional dose may benefit the patient further progression of bone metastases

# CHOCKING

Chocking is the inability to breath as a result of acute obstruction of the pharynx, larynx or trachea.

This can be due to local tumour or neurological swallowing difficulties, as well as a more general obstruction

# Cont’

Assessment and Mgt of chocking from local tumour

- Acknowledge the patients and family fears
- Discuss the intervention truthfully with pt and family
- High dose steroids may be useful to reduce the swelling around the obstructing tumour
- Palliative radiation if available may also help
- Midazolam 5mg sc can help to sedate the pt and reduce anxiety
- Rectal diazepam can be used especially in community

# HYPERCALCEMIA

It is a threatening metabolic disorder associated with cancer. Its when the serum level of calcium is > 10.5mg/dl. It is common in pts with breast cancer, multiple myeloma & head, neck & renal tumours

Causes

Lytic bone lesions, thus causing calcium to be released from the bone along with a ↓se in the excretion of urinary calcium

# Signs and symptoms

- General malaise
- Nausea & vomiting
- Cardiac arrhythmias
- Severe dehydration
- Confusion and coma
- Anorexia
- Constipation
- Thirst and polyuria
- Polydsphagia
- Drowsness

# Assessment and Mgt of hypercalcemia

- Rx of hypercalcemia can markedly improve symptoms  even in pts with advanced disease
- Proper Mgt of hypercalcemia makes end of life care & Mgt less traumatic for the pt and the carer
- The pt may be admitted for hydration & biphosphonate therapy ( e.g. disodium pamidranate 60-80mg in Nacl 0.9%, 500ml over 2-4hrs) . However this Rx may not be available due to cost

# SPINAL CORD COMPRESSION

In SCC the spinal cord is compressed causing neurological symptoms

- Cord compression occurs when there is extrinsic or intrinsic obstruction to the spinal cord
- If it’s no managed quickly, a progressive turn into irreversible neurological damage (e.g. paralysis)
- Be alert for pts with new thoracic back pain

# causes

- Vertebral metastasis leading to collapse is the most common cause
- Epidural infiltration
- TB should be considered
- Less often there is vascular interruption

# Signs and symptoms

- Backache; which may radiate circumferentially & where the pt may complain of a tight band around the waist
- Weakness in the lower limbs
- Abnormal sensations in he lower limbs; pain, needle tingling sensations, crawling insects etc
- Bladder symptoms
- constipation

# Assessment

- A quick proper assessment can help to arrive at an actual diagnosis, w/c can help to maintain or restore motor functions in the pts who could otherwise face disabling for the rest of their life
- SCC is common in pts with advanced cancer of the breast, lungs or prostate gland
- A careful history & neurological examination shd be made including looking for what sensory level applies
- Ask about bladder and bowel sphincter function

# Mgt

- Most important is to think of the Dx & to start Rx before irreversible neurological loss occurs
- Start high dose steroid dexamethasone 16mg in divided doses
- Arrange appropriate investigations such as
  x-ray, bone scan, CT mylogram or MRI scan depending on availability
- Refer for urgent (1day radiotherapy if available)
- Surgery may also be considered depending on the pts condition & availability of facilities & surgeon
- Once neurological loss has occurred it's often irreversible but good rehabilitation will maintain function & prevent complications

# SUPERIOR VENACAVA OBSTRUCTION

It’s the partial or complete obstruction of blood flow thru the superior venacava into the right atrium.

It usually results in impairment of venous return

Causes

External compression by a tumour or lymph nodes or thrombosis as a result of compression

# Signs and symptoms

- Dyspnoea
- Cough
- Dysphagia
- Headaches
- Visual change
- Facial/upper body swelling including arms

This condition is common in pts having tumours in the mediasternum i.e. bronchial carcinoma, cancer of the breast and lymphoma

# Assessment

- Examination may reveal engorged conjuctiva, periorbital oedema, dilated neck veins and collateral veins on arms and chest wall
- Late signs include; pleural effusions, pericardial effusion and strodor

# Mgt

- In advanced disease, the pt needs relief of their acute symptoms
- Give high dose steroids (dexamethasone 16mg per os or IV if available), urgent radiotherapy, at the same time treat dyspnoea symptomatically with morphine (5mg 4hrly) or benzodiazepine
- Practical mgt of dyspnoea is also important e.g. teach the pt how to breath slowly & encourage calm enviroment
- Without treatment, SVCO carries a very poor prognosis

# SEVERE UN CONTROLLED PAIN

This should be assessed and managed as per the WHO analgesic ladder

# SEIZURES

A seizure is a symptom of irritation of the central nervous system resulting in excess & abnormal neurological discharge. A seizure occurs when large numbers of neurons discharge in an unusual manner

An acute seizure refers to 5 minutes or more either continuous seizures or two or more seizures between which there is incomplete return to consciousness. Pts who are at risk of developing seizures are those with primary or metastasis of cerebral tumours

# Care

- Anticonvulsants can be used & prophylactic measures are usually recommended in pts who have had seizures
- Phenytoin & phenobarbitone are commonly use anticonvulsants
- If apt is unable to tolerate oral medication, phenobarbitone can be Subcutaneously
- While having a seizure, pt should be protected from self-injury, turned on the side
- If its hypoglyceamia causing the seizure, IV glucose shd be given
- Explain to the family about the likelihood of the seizures
- Making the pt comfortable, preventing suffering & meeting the needs of family members is the sole priority

# SYMPTOMS AND SYMPTOM CONTROL

**Commonly experienced symptoms by terminally ill patients**

- Nausea and vomiting
- Mouth sores and difficulty swallowing
- Hiccup
- Diarrhoea
- Constipation
- Breathlessness
- Urinary retention
- Bladder spasms

# The principles of symptom management

- Assess the cause of a particular symptom as correctly as possible
- Explore any other symptoms other than the one you have identified
- Explain the cause and the importance of treatment to the pt and their family
- Discuss the different Rx options with the patient and family
- Do not forget that symptoms do change as the disease advances and drug tolerance changes as the body weakens with disease spread

# Cont’

**Holistic assessment**

- Careful and detailed history
- Relevant clinical examination
- Appropriate investigations
- Establish diagnosis
- Explain everything to the patient.

# Cont’

**Detailed history**

- First step in effective management of a patient’s symptoms is undertaking a detailed history. This enables us to diagnose the possible cause of the symptoms.
- We must remember the concept of “Total Care” and resist the temptation to focus on physical aspects of history.

**Physical examination**

- It should be focused, thorough and detailed
- Direct examination towards the system of presenting symptom.

# Cont’

**Investigations**

- Appropriate investigations to guide clinical decision making
- May not be a realistic option: financial, location, resources
- Do not delay starting treatment pending investigation results.
- Establish Diagnosis

# Cont'

**Establish Diagnosis**

- Cause of symptoms may be due to:
- The disease itself
- The treatment for the disease
- Disease related debility
- Concurrent disorders.
- What is the underlying mechanism? E.g. hypercalcaemia, raised ICP

# Cont’

**Explanation to patient**

- Explain the possible causes of symptoms to the patient and family
- A simple explanation of the cause and nature of the symptoms to the patient may help to reduce fears or anxieties
- Open and regular communication is essential.

# Symptoms by a terminally ill patient and their management

**GIT symptoms**

**Nausea and vomiting:** most of cancer pts experience this at a point in time. It can arise from many different causes but it can be due to the following

- Poor stomach emptying w/c could be as a result of drugs such as opioids and constipation, stomach and bowel conditions
- Inflammation or swelling in the head as a result of brain tumours, meningitis, malaria and ear infection
- Infectious diarrhoea
- Constipation, abdominal and pelvic tumours
- Partial or complete bowel obstruction

# Management of nausea and vomiting

Pharmacological and non pharmacological interventions should be considered

- It's very important to treat the underlying cause
- Give antiemetic such as metochlopramide
- Dietary modifications such as ↑sing the fluid intake, if appropriate & if possible advise small regular meals, low odour food
- Relaxation techniques can be beneficial
- In raised intracranial pressure, corticosteroids can be given
- Oral care after each vomiting

# Symptoms of mouth sores and difficulty swallowing

As you may know infection and ulceration of the mouth are common and very distressing symptoms for pts with advanced cancer or HIV

The sores can be due to oral & oesophageal candidiasis. But take note that many problems with the mouth may be prevented by good mouth care, keeping the mouth moist and treating infections quickly

# Management

- Oral candidiasis can be managed by applying GV paint to areas that are affected 8hrly or using Nystatin drops 1-2mls 6hrly after food
- For oesophageal or recurrent oral candidiasis fluconazole 200mg OD for 3days. In cases of secondary bacterial infection, it should be treated with antibiotics
- As a nurse it's important to keep checking the mouth, teeth, tongue and palate on a regular basis for dryness, inflammation, candidiasis and infection
- Its also important to maintain good oral care for the pt
- In case of a dry mouth, the pt can take small sips of water or such pieces of fruits as pineapple or passion fruit
- In case of oral sore analgesics have to be used for pain

# Diarrhoea

Acute episodes of diarrhoea do not usually need drug Rx except fluid replacement. Diarrhoea with blood or high fever may however need antibiotics such as ciprofloxacin. At times diarrhoea may at the same time be persistent (lasting for more than 2wks). This is distressing for the patient and needs to be controlled immediately

# Management

The cause should be treated in case of infections

- Dehydration with ORS but in case it’s so severe, then IV fluids may be given
- Review the pt’s medication (e.g. antibiotics or ARVs) because some of them may cause diarrhoea
- Given plenty of drinks and use of ORS if diarrhoea is frequent or large volumes
- Encourage the pt to take sips of water or any other fluids frequently rather than a large drink al at once

# Cont’

- Suggest the pt eats small amts of food but frequent rather than a large meal
- Foods such as yoghurt, rice, bread are good for diarrhoea
- Encourage good hygiene such as hand washing after using a latrine if possible
- In case the pt is bed ridden, maintain clean and dry beddings to prevent skin breakdown

# Constipation

About 50% of terminally ill pts suffer from constipation. If possible the pt should be examined to find out why they are not passing stool. In terminally ill pt constipation can be due to a mass in the rectum obstructing the stool, it can as well be due to the side effects of medication such as morphine or codeine

# Management

- Encourage plenty of water or other drinks
- Encourage fruit and vegetables in the diet
- If available pawpaw seeds can be chewed (5-30 seeds can be chewed at night) or crushed and mixed with water to drink
- A spoonful of cooking oil can as well be given to the patient
- Appropriate laxatives such as bisacodyl 5mg at night ↑sing to 15mg if needed, senna can be given

# Respiratory symptoms

**Breathlessness:** It's a frightening symptom in advanced illness and almost always causes anxiety for the pt and their family. The anxiety needs to be managed as well as the breathlessness. Breathlessness can be due to anaemia, asthma, heart failure, pleural effusion or cough

# Management

- The cause of breathlessness should be treated
- Find the most comfortable position for the pt especially the sitting up position
- Nurse pt in a well ventilated room to allow air to circulate and you can use a fan if available
- Teach the pt to move slowly and carefully to avoid increasing breathlessness
- If the pt is very anxious; counsel them & explain that their breathlessness will improve or manage the anxiety
- If it can't improve, give morphine 2.5-5mg 4hrly and Diazepam 2.5-5mg TDS
- If shortness of breath is due to a swelling obstructing the respiratory tract, Dexamethasone 8-12mg OD may help

# Hiccup

Hiccups are as a result of irritation of the phrenic nerve on the neck of the mediastinum or irritation of the diaphragm from above. Commonly seen in majority of dying patients.hiccups can be distressing and exhausting for the pt if they are frequent & they don’t resolve quickly

Tumours that lead to distension of stomach, tumours of lungs, cancer of oesophagus, renal failure & hepatomegally are commonly associated with hiccups. But at the same time it can be cental that is, from the brain

# Management

To stop hiccups, get the patient to;

- Breath from a paper bag
- Swallow for example dry bread
- Try nursing the pt while in sitting up position
- Medication such as Metochlopramide 10-20mg 8hrly, Haloperidol 3mg at night or Chlorpromazine 25-50mg at night may be prescribed

# Gastro-oesophageal reflux

As you may know, this is common when there is pressure on the diaphragm from the abdominal tumour or ascites and l a neurological disorder

Management

- It's helpful to nurse the pt in a sitting up psn
- Give drugs after food
- Try giving milk
- In case the pt is receiving NSAIDs, they may need to be stopped
- Simple antacids such as Magnesium trisilicate 10ml 8hrly but in cases it's persistent, cimetidine 200mg or Ranitidine 300mg 12hrly or Omeprazole 10-20mg at night may be prescribed

# Urinary symptoms

**Urinary retention:** In terminally ill pts it can be due to; faecal impaction as a result of constipation, UTIs, drug induced e.g. with Amitriptyline and opiates, but this is usually temporary or spinal cord compression

**Management**

- Treat the cause
- Catheterization will relieve the retention
- Sometimes the problem may resolve once the urine has been drained. Although in other circumstances the catheter may be needed for the long term management

# Cont'

**Bladder spasms**: these are sudden & severe pain w/ c ma be felt in the bladder and urethra esp in pts with bladder or prostate cancer but it can also follow catheterization or bladder infection

**Management**

- Encourage the pt to take a lot of fluids
- Drugs such as Amitriptyline 25-50mg at night, Hyoscine butylbromide 10-20mg 6hrly may be prescribed by the doctor

# Neuropsychiatric symptoms in palliative care

- **Neuropsychiatric symptoms**
- Distress
- Anxiety/panic disorders
- Depression
- Confusion/Delirium
- Denial
- Anger
- Grief
- Withdrawal

# Cont'

**Risk factors**

- Previous history of depression
- Previous substance abuse
- Concurrent life stresses
- Isolation
- Uncontrolled pain aor other symptoms
- Medication e.g. steroids, vincristine, interferon
- Complications of cancer e.g.brain metastasis
- Elderly patients/young patients

# Cont’

**Impact**

- Poor quality of life
- Added stress to family /carers
- More likely to disengage with treatment
- At higher risk of suicide
- Make more frequent requests foe euthanasia or physician assisted suicide

# Cont’

**Presentation**

- Low mood. Tearfulness, irritability and distress
- Withdrawal, loss of interest or pleasure in daily activities
- Feelings of hopelessness, helplessness, worthlessness or guilt
- Suicidal behaviours, requests for physician assisted suicide

# Cont’

**Treatment**

- Coordinating care
- Patient preferences
- Diagnosis
- Severity
- Possible contra-indications
- Possible side effects-good or bad
- Risk of suicide
- Baseline assessment
- Regular review of treatment

# Cont’

- Psychological therapy
- Counseling
- Cognitive behavioral therapy
- Problem solving therapy
- Creative therapy
- Pharmacological therapy
- ✓ Citalopram
- ✓ Mirtazapine
- ✓ Sertraline – first line treatment
- ✓ Second line: Amitryptline

# PAIN AND ITS CONTROL IN THE TERMINALLY ILL

**Definition of pain**

- Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage.
- Pain is what the experiencing person says it is, existing whenever the experiencing person says it does.
- “Pain is what the patient says it hurts”
- Pain is subjective-individuals create their own definition of pain based on their experience.
- Pain is the commonest symptom experienced by the dying and certainly the most feared.
- It is present in 98% of patients with cancer and HIV/ AIDS.

# Cont’

- Cancer pain is usually constant and increases with progression of the disease.
- In developing countries where less than 5% of cancer patients have access to chemotherapy or radiotherapy, the natural history of pain is that it is progressive up to the time of death
- In an African study of patients with stage IV AIDS, the commonest pains were:

# Cont’

- Lower limb pain (66%) due to peripheral neuropathy
- Mouth pain (50.5%)
- Headache (42.3%)
- Throat pain (39.8%)
- Chest pain (17.5%)

# Cont’

**Why does acute pain exist?**

- Acute pain exists as a useful mechanism for alerting an organism to the presence of harmful (or potentially harmful) stimuli in the environment e.g. excessive heat or cold.

# Cont'

**Acute pain in cancer**

- Pain can occur in patients with cancer due to:
- Direct effects of the disease, e.g. tumor infiltration of pain sensitive structures
- Effects of the treatment e.g. radiotherapy- injures visceral, musculoskeletal and nervous tissues.
- Surgery, chemotherapy and radiotherapy are all associated with potentially painful side effects.

# Types of pain

- Pain can be described according to its temporal course: i.e. acute or chronic
- Pain can also be described according to its physiological mechanism i.e. Nociceptive or Neuropathic.
- Often more than one pain is present.
- In order to assess and treat pain effectively you must identify what type of pain is occurring.

# Nociceptive pain

- This is triggered by the activation of nociceptors in superficial skin, viscera or deeper musculoskeletal tissue. Nerve path ways are intact.
- The feeling of pain is a normal response to a noxious stimulus.

**Types of nociceptive pain**

**Somatic pain**

**Cause**

- Due to activation of nociceptors in:
- Cutaneous and deep musculoskeletal tissues.

# Cont’

- Skin, bone, joint, muscle, vessels and mucous
- E.g. cancer- bone metastasis, non-cancer: arthritis, cellulitis, fracture, post surgical incision pain.
- **Description**
- Pain is well located, described as aching, squeezing, throbbing and gnawing sensation.
- **Incidence**
- 72% of patients with cancer have somatic pain

# Cont’

**Visceral pain**

**Cause**

- Due to activation of nociceptors located in the viscera.
- visceral compression by the tumor
- visceral infiltration by the tumor
- e.g. cancer liver metastasis, pancreatic cancer and non-cancer conditions like myocardial infarction, peptic ulcers.

# Cont’

- **Description**
- It is poorly localized
- Feeling of deep pressure, crapping or squeezing
- Might be associated with dizziness, nausea
- Pain is often referred to cutaneous sites which may be remote from the site of the tension.

# Cont’

- **Treatment**
- Simple analgesia
- Antispasmodics (to reduce spasms)
- Steroids (to reduce inflammation)
- Incidence: 35% cancer patients have visceral pain.

# Neuropathic pain

- It is common
- It is important to diagnose it because its mechanism and treatment are very different from that of nociceptive pain.
- It results from **damaged nerves.** There is damage to peripheral and or central nervous systems

# Causes

- Tumor compression in peripheral nerves or central nervous system
- Tumor infiltration in peripheral nerves or central nervous system
- Chemotherapy
- Radiotherapy
- HIV infection
- Herpes zoster
- Diabetes mellitus
- Stroke

# Cont’

- **Description**
- It is often severe
- It is different in quality to nociceptive pain
- Constant dull ache, pressure
- Burning, pricking in nature, pins and needles, creatures crawling under the skin, shooting.
- **Treatment**
- Antidepressants, anticonvulsants, +/- Opiates
- **Incidence**
- 40% cancer patients have neuropathic pain.

# Cont’

**Factors that influence pain**

- The patient’s mood
- The patient’s morale
- The meaning of the pain for the patient e.g. the meaning of pain in advanced cancer is
- “I ‘m incurable”: I ‘m going to die.

# Cont’

- **Pain is increased by:**
- Discomfort
- Insomnia
- Fatigue
- Anxiety
- Fear
- Anger
- Sadness
- Depression
- Boredom

# Cont’

**Pain is decreased by:**

- Relief of other symptoms
- Understanding
- Companionship
- Creative activity
- Relaxation
- Reduction in anxiety
- Elevation in mood
- Analgesics
- Anxiolytics
- Antidepressants.

# Principles and management of pain

There are two principles of pain management

**1. Total pain**

- The concept of total pain was developed by Cicely Saunders in 1960s.
- She acknowledges that pain is not just a physical phenomenon. It encompasses physical, psychological, social and spiritual aspects of suffering.
- **Physical**: undesirable effects of treatment, insomnia, chronic fatigue

# Cont’

- **Psychological**: anger at delays in diagnosis, anger in treatment failure, disfigurement, fear of pain/ death, feelings of helplessness, anger at friends who do not visit.
- **Social**: worry about family, Worry about finance, loss of job, loss of income, loss of social position.
- **Spiritual**: Why has this happened to me? Why does God allow me to suffer like this? Is there any meaning or purpose in life?

# Cont’

2. **Holistic pain**

- Clinical care
- Social support
- Spiritual support
- Physical support

# Cont’

**The impact of pain**

- Severe pain in advanced cancer patients has negative physiological and psychological complications that may worsen an already bad situation.
- Interaction of pain with other symptoms (e.g. nausea, constipation, shortness of breath, depression, anxiety, insomnia) may worsen the patient’s condition.
- The patient’s functional status is further impaired.
- The patient’s autonomy is challenged.
- The patient’s dignity is challenged.
- The patient and family may interpret pain as impending death.

# Cont’

**Barriers to pain management**

- Inadequate pain assessment
- Inadequate knowledge about pain and its management
- Concerns about possible side effects of pain medications
- Patient and doctor’s attitudes, fears and misconceptions about pain and opioids.
- Poorly accessible or unavailable pain management services.

# Principles of pain assessment

Pain is subjective. Suffering is characterized as a person's evaluation of the significance of an event such as pain, or the meaning of an event in relationship to self and to the quality of life

"Pain is what the patient says it is, and exists whenever the patient says it does"

# Assessment of pain

Ongoing comprehensive assessment is the foundation of effective pain management, including interview, physical assessment, medication review, psychological and physical environment review and the appropriate diagnostics

Assessment must determine the cause, site, quality & radiation, effectiveness of treatments and the impact on quality of life for the pt and family

# Goal of pain assessment

- To capture the individual's pain experience in a standard way
- To help determine the type of pain and possible aetiology.
- To determine the effect and impact the pain experience has on the individual & their ability to function
- To aid communication between interdisciplinary team members

# Pain assessment using acronym P,Q,R, S,T

**P=Position**

- Where is the pain?
- Can you point to where the Pain is?
- Does it spread?
- Put an X to where it hurts most.

**P=Precipitating factors**

- Does anything make the pain much once? E.g. eating, opening bowels, movement.

# Cont'

**P=Palliative factors**

- Does anything make the pain better?
- Better when staying still?
- Better when bowels are open?
- Better after wound has discharged?
- Better if use hot or cold compress?
- Better if praying?
- Better when with friends?
- Have you tried any medication/painkillers/herbs? Do they help?
- Did treatment take away all or some of the pain?

# Cont’

**Q=Quality**

- What does the pain feel like to you?
- What words would you use to describe your pain? Nociceptive or somatic pain?

**R=Radiation**

- Where does the pain start?
- Does it spread anywhere else?

# Cont’

**S=Severity**

- How severe is the pain?
- Can you score your pain out of 5?
- How does it affect your life?
- Does it prevent normal activity?
- Preventing sleep?
- Preventing movement?
- Preventing sitting?
- Preventing eating?

# Cont'

**T=Timing**

- How long have you had the pain?
- Is the pain constant?
- Does the pain come and go?
- Is it worse at any particular time of day or night?

**T=Thinking**

- Explore the patient's fears about the pain. What do you think is causing the pain? What does the pain mean to you?
- Some answers: I 'm being punished. I 'm going to die. There is no hope. I have to suffer it is my destiny. I 'm being eaten away.
- Thoughts about current and previous Rxs and medications

# How to measure pain

It’s virtually impossible to measure a person’s pain objectively. Most experts say that the best way to find out how much pain a person is enduring is by a subjective pain report

There are many different mtds for measuring pain & its severity. Health care professionals say it’s important to stick to whatever system or tool you choose for  a specific pt all thru.

Here is a list of some pain measures used today

# cont'

1. **Numerical rating scales**.

The pt is given a form w/c asks him to tick from 0-10 what his level of pain is. 0 is no pain, 5 is moderate pain and 10 is the worst pain imaginable

| 0 | | | | Please rate the pain you have right now | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| No pain | 2 | 3 | | 5 Moderate pain | 6 | 7 | 8 | 9 | 10 Worst pain |

# Cont’

1. **Numerical rating scales.**

The pt is given a form w/c asks him to tick from 0-10 what his level of pain is. 0 is no pain, 5 is moderate pain and 10 is the worst pain imaginable

| 0 | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|
| No pain | Little pain | Mild pain | Moderate pain | Severe pain | Overwhelming pain |

## Cont’

pain score: Visual analogue scale of 0-5.

1. you can use your fingers of the hand
2. Use of dffnt facial expressions

# Cont’

The numerical rating scales are useful if you want to measure any changes in pain, as well as gauging the pt’s response to pain RX. If the pt has dyslexia, autism or very elderly and has dementia, this method may not be the best tool

# Cont’

2. **Verbal descriptor scale**

This type of scale exists in many different forms. The pt is asked Qns and responds verbally choosing from such terms as mild, moderate, severe, no pain, mild pain, discomforting, distressing, horrible and excruciating

Elderly pts with cognitive impairment, very young chn, & pple who respond better to verbal stimuli have a better completion rates with this type of scale, compared to written numerical scale

# Cont’

3. **Faces’ scale**

The pt sees a series of faces, the 1st is calm & happy, 2nd less so, etc and the final one has an expression of extreme pain. This scale is used mainly for children, but can also be used for elderly pts with cognitive impairments. Pts with autism may respond better to this type of approach

# Cont’

4. **Brief pain inventory**

It’s much more comprehensive questionnaire. Not only does it gauge current level of pain, but also records the peaks & thoughts of pain during the previous days, hw pain has affected mood, activity, sleep pattern & hw it may have affected pt’s interpersonal r/ship. The questionnaire has diagrams w/c pt shade parts where pain is located

# THE THERAPEUTICS OF PAIN

- The WHO states that freedom from cancer pain and pain caused by other diseases like HIV/AIDS should be a Basic Human Right.
- **Principles of pain control**
- Consider the cause.
- Diagnose the cause of pain
- Choose the correct analgesic ladder
- Treat underlying cause if possible.

# Cont’

- **Principles of Rational Analgesic Prescribing**
- By mouth
- By the clock
- By the ladder
- By the patient
- Attention to Detail/Adjuvants.

# Cont’

**By the mouth**

- If possible always give analgesics **by mouth**

**By the clock**

- Give analgesics at regular intervals
- Give the net dose of analgesia before the previous one has worn off
- Titrate the dose against pain

**By the ladder**

- The sequential use of analgesics
- Using the WHO ladder (1986).

# Cont’

**By the patient**

- Patient should be involved in decisions concerning his/her pain
- Feedback from patient on tolerance/side effects from analgesics is essential
- There are no “standard” doses for opiate drugs. The right dose is the dose that relieves the patient’s pain.

# Cont'

**Attention to detail/ Adjuvants**

- Regular laxatives are needed in all patients who receive opiates except those suffering from persistent diarrhea.
- Antiemetics are seldom required with initial morphine use in African patients.
- Not all pain responds to opiates and the ladder.
- Opiate semi-responsive:
- Bone pain-NSAID+/- opiates

# Cont’

- Nerve compression- steroid
- Increased edema-ICP-steroid
- Inflammation- steroid
- Opiate resistant:
- Muscle pain/spasm-muscle relaxant
- Neuropathic pain- tricyclic antidepressants e.g. amitriptyline and anticonvulsants.

# Cont'

- **WHO Analgesic Ladder**
- The WHO developed a method of using analgesics that enable the control of pain in up to 90% of cancer patients (WHO 1996).
- It is made up of three (3) steps
- If the drug ceases to be effective a strong drug should be prescribed and the ladder climbed up another step
- Treatment should move step-wise up and down the ladder as appropriate.

# Cont’

- **Step 1 – Non-Opioids**
- Drugs: paracetamol and any NSAID. Paracetamol 1gm tds, Ibuprofen 4oomg tds, Diclofenac 50mg tds.
- If one NSAID doesn’t work try a different one
- Paracetamol and NSAIDs can be given together.
- Step one should be continued when a patient moves up the ladder.

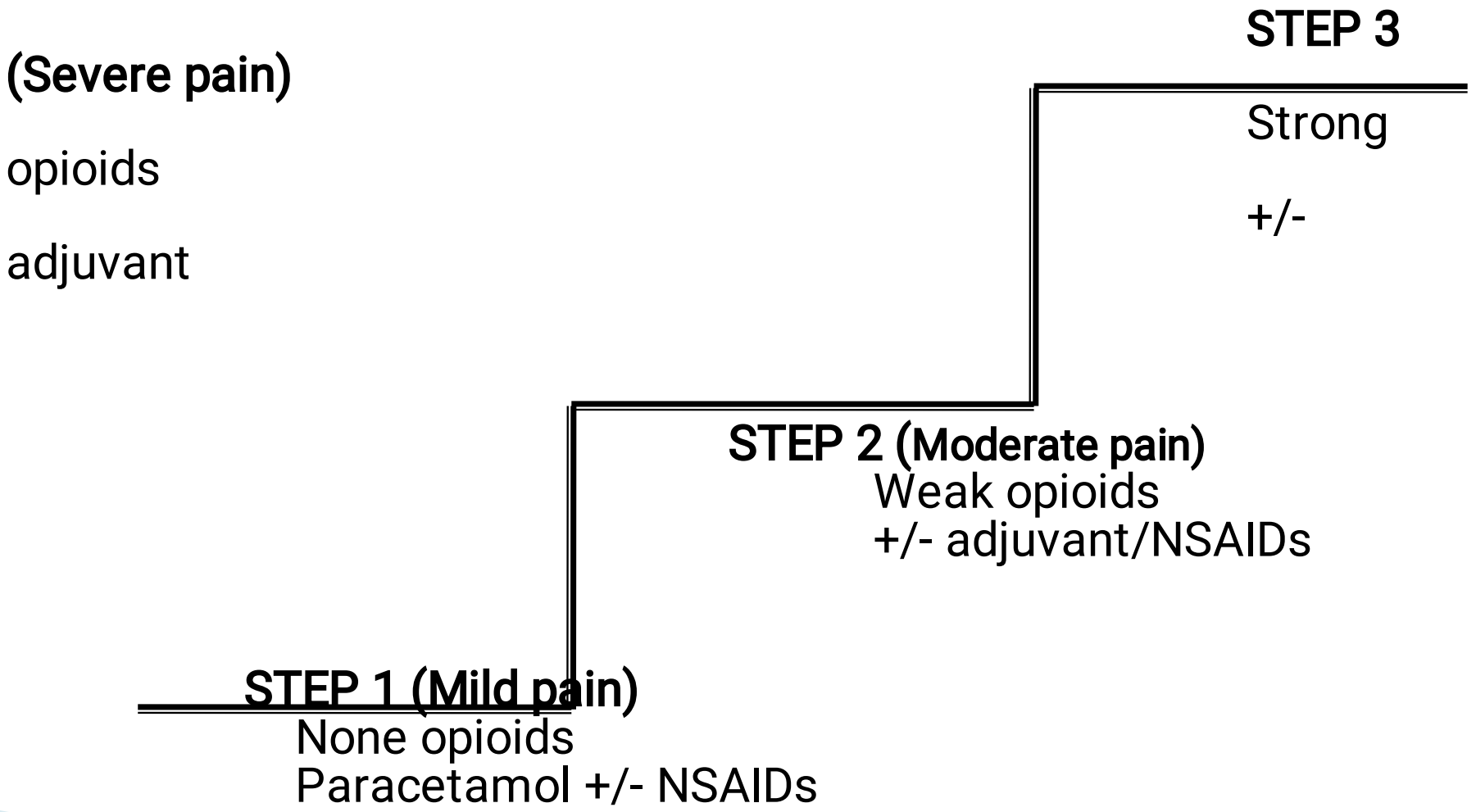
# Cont’

- **Step 2 – Weak Opioids**
- Drugs: Codeine, Tramadol
- These drugs have a ceiling effect. Increasing dose does not give increased pain control, and also more side effects.
- If this fails to achieve pain control, substitute weak opioid for strong opioid.
- This step is often deliberately omitted.

# Cont’

- **Step 3 – Strong Opioids**
- Drug: Morphine. Liquid morphine is the most available preparation
- It is prepared in different strengths:
- Weak Morphine (green): 5mg/5ml
- Strong Morphine (red): 50mg/5ml
- Very strong Morphine (blue): 100mg/5ml

# WHO analgesic ladder



# Cont’

The WHO advocates that these analgesics should be given “by the clock” that is every 3-6hrs, rather than “on demand”. This stepped approach of administering the right drug, dose at the right time is inexpensive & generally effective in managing acute pain

# Advantages of the analgesic ladder

- Simplicity, as only a few analgesic groups are used
- Flexibility to a large variety of pain situations and also to prescribers globally
- Safety in that safe drugs are used first in their lowest effective dose
- Emphasis on multi-model analgesia

# Disadvantages

- It may be too simplistic for Mgt of certain types of pain e.g. neuropathic pain or for those who are opioid dependent
- It suggests that analgesics should be administered orally, w/c may be occassionally inappropriate e.g. w/n pts are “Nill per once”

# MANAGEMENT OF PAIN

Pain can be managed using both drug and non drug measures. w/n managing pain, remember its source and cause. Also remember it can be due to;

- D’se it self e.g. HIV, cancer, bone metastases
- Opportunistic infection
- Treatment e.g. post operative adhesions', ART
- Concurrent disorder e.g. DM and SCD

# Management of pain lies under the following

- Drug therapy
- Surgery
- Good communication
- Relaxation system
- Massage
- Aromatherapy
- Spiritual therapy
- Counseling
- Heat or cold

# Cont'

**Principles of prescribing Morphine**

- The starting dose of oral Morphine is 2.5-5mg four hourly (5mg/5ml)
- Double dosing at night
- Breakthrough dose is the same in between regular if required
- Always review after 24hrs. Consider increasing the dose by ⅓ to ½ if pain is not relieved by 90%.
- There is no maximum dose (In Uganda 30mg /24hrs is most common dose)
- In renal impairment and liver disease, the dose and frequency should be reduced.

# Myths and fears surrounding the use of Morphine

**Why use Morphine?**

- WHO says “In patients with severe pain, MORPHINE, a strong opioid is the drug of choice”.
- WHO says, “freedom from cancer pain should be seen as a RIGHT of a very cancer patient and access to PAIN therapy as a measure of respect for this right”.
- WHO says, “In most parts of the world, the majority of cancer patients present with advanced disease”. For them, the only realistic treatment option is pain relief and palliative care.

# Cont’

**Myths and Fears, misconceptions**

- **Myths**
- Patients, their relatives and unfortunately many health professionals have beliefs about morphine that affect their acceptance of it as treatment for pain. They include:

# Cont'

**1. Tolerance (Myth)**

- Increasing the dose of morphine to control pain, i. e. to titrate the dose against pain is thought by some patients and some physicians as ***tolerance.*** In palliative care the ceiling dose of morphine is that dose for that individual patient which controls the pain. <u>This is not tolerance to morphine.</u>
- The need for an increased dose of morphine does not mean that the patient is becoming addicted.

# Cont'

**2. Physical dependence (Myth)**

- Abrupt discontinuation of an opiate usually causes withdrawal symptoms. The symptoms are rhinorrhoea, lacrimation, diarrhea, anxiety, yawning, chills, hyperventilation, hyperthermia, muscle aches and vomiting. However, if withdrawal is gradual for over 2-3 days these symptoms are alleviated. This is not physical dependence

# Cont’

**3. Addiction (psychological dependence) (Myth)**

- This problem is very rare. It is a reflection of pathological behavior associated with non-medical use of morphine and related opioids.

# Cont’

**4. Cognitive impairment (Myth)**

- When morphine therapy is initiated, there may be some sedation and a temporary attention deficit, manifested by reduced recent memory. These generally disappear after three to five days. This is not addiction.

**5. Lethality (Myth)**

- Morphine does not kill when properly prescribed in gradually increasing doses according to need. Should overdose occur, Naloxone controls the situation.

# Cont’

**Fears**

**1. A last resort before death? (F)**

- Some people fear that morphine is prescribed as a last resort when the patient is going to die. Morphine is used to relieve pain at various stages of illness and not just when the patient is about to die.

**2. Hastening death (F)**

- Some people fear that morphine will hasten death. When used appropriately, morphine does not affect the time of death. Patients die from the effects of advanced cancer or AIDS, not as a result of morphine. Morphine allows relief of pain so that patient can function effectively.

# Cont’

**3. Morphine is reserved till the end (F)**

- Some people mistakenly think that morphine should be reserved till the end. They fear that if morphine is taken early in the course of illness it may not be effective later when pain is more severe.

**4. Respiratory distress (F)**

- Some people believe that morphine can cause breathing problems if the person also has a lung problem. Breathing difficulties can occur as a result of morphine overdose. However this can be avoided by taking low doses initially and stepping up the dose gradually.
- Morphine can be used to reduce distress caused by severe cough or severe breathlessness.

# Cont’

**5. The elderly should not be given ,morphine (F)**

- Elderly patients with cancer pain respond just as well to morphine as younger patients. However, they are more prone to side effects. Therefore, smaller doses should be taken and increments should be gradual.

**6. Injection morphine is better than oral morphine (F)**

- Morphine is well absorbed when given orally. Oral (liquid) morphine is very cheap compared to tablet or injectable forms. Injection morphine should only be given in patients who cannot take orally e.g . severe vomiting.

# THE ROLE OF SURGERY, RADIOTHERAPY, CHEMOTHERAPY IN PALLIATIVE CARE

The RX options for pts with cancer are;

- Surgery
- Chemotherapy
- Hormonal treatment
- Radiotherapy and
- Palliative care

# Cont’

The burdens and benefits of palliative RX are;

**Potential benefits;**

- Reduce tumour size
- Symptom control
- Prolonged survival
- Psychological impact of receiving treatment
- Improve quality of life

# Cont’

**Potential burdens;**

- Side effects
- Financial burden
- Travel from home
- Admission to hospital
- Decreased quality of life

# Cont’

**CHEMOTHERAPY**

- Is the treatment of cancer with drugs (anticancer drugs) that can destroy cancer cell.
- The term chemotherapy usually refers to cytotoxic drugs that affect rapidly dividing cells
- Most forms  of chemotherapy target all dividing cell & although some degree of speficity may come from the inability of many cancer cells to repair DNA damage, while normal cells generally can
- Hence chemotherapy has the potential to harm healthy tissue, esp those that have high replacement rate (e.g. intestinal lining). These cells usually repair themselves after chemotherapy

# Principles of chemotherapy

- High dose of chemotherapy are most effective
- Combination of chemotherapy avoids drug resistance (combination therapy)
- Sequesnce of administration of drugs is important, esp if one drug is used to modulate or ↑se the activity of the 2$^{nd}$ drug
- Resistance of drugs allow cancer cells to survive, tumours can become resistant to more than one drug

# Examples of cancer chemotherapy drugs

- Methotrexate
- Fluoropyrimidine
- Cytosine Darabiniside
- Vinca alkaloids (vincristine, vinblastine, videsine)
- Antitumours antibiotics( Doxorubicin, Daunnorubicin and Mitoxantone)
- Dactinomycin (Actinomycin D)
- Cytotoxic drugs(Azarthioprime, cyclophosphamidechlorambucil)
- Corticosteroids(Hydrocortisone, cortisone)

# Examples of tumours responsive to chemotherapy

- Lymphomas
- Leukaemia
- Teratomas
- Kaposis sarcoma
- Breast cancer
- Colorectal cancer

# Indications for chemotherapy

- If the tumour needs to be reduced
- Symptomatic response(e.g. pain, discharge, bleeding breathlessness etc)
- Increased survival
- Emergency situations

The indications must balance or outweigh the potential side effects

All in all performance status is important

# Cont’

**Some side effects of chemotherapy**

- Nausea and vomiting
- Hair loss(alopesia)
- Myelosuppression
- mucositis

# Cont'

**The role of palliative care professionals in chemotherapy**

- To give advice to patients
- Management of symptoms(side effects)
- Discuss with the oncologists/consultants on the best option

**Note;** confirmatory diagnosis of cancer is abiopsy

# Cont’

**The following sites with cancer are not good for chemotherapy**

- Cervix
- Head and neck
- Genitourinary
- Arcoma e.g. Rabdomyosarcoma

**The following sites with cancer are good for chemotherapy**

- The breast
- Kaposis sarcoma
- Lymphosis
- Gastrointestinal

# Cont'

**HORMONAL TREATMENT**

- Under here we consider the type of tumour
- Some tumours are stimulated by specific hormones
- Blocking these hormones can reduce tumour growth and improve symptoms & prognosis
- Some agents are affordable & can be used by non specialists

# Cont'

**Examples**

1. Breast cancer. Use Tomoxifen, it blocks oestrogen hormone & hence reduces the growth of the rapid growing cells, i.e. the tumour will reduce & pt will improve and become happy
2. Prostate cancer. Use Goseretin or Zoladex. Surgical options are male castration, or removal of the testes.

# Cont’

**RADIOTHERAPY**

This is the therapeutic use of ionizing radiation to kill cancerous cells

Mechanism of action

It’s by damaging the DNA of the cell that are affected. Only treats the area that the x-ray beam is aimed at and therefore it can cause side effects within this area

# Cont’

There are 3 main types of radiotherapy

1. External beam
2. Brachy therapy
3. Radio isotope (orally or I.V)

# How Radiotherapy is given

1. **External beam radiotherapy**

Different types, but cobalt used in Uganda.

Megavoltage allows penetration into deep tissues with relative sparing of superficial tissues

It therefore requires thorough planning be4 treatment to ensure correct area is treated

# Cont'

**2. Brachy therapy**

Radiation source is applied close to the tumour. The most common in uganda is for cervical cancer & the therapy used is caesium rods inserted for around 12hrs

**Indications for Radiotherapy**

- Bleeding
- Ulceration
- Masses
- Pain like in bone metastases
- Obstruction esp GITe.g. ca oesphagus, rectum, lungs
- Cosmesis e.g. ugly ulcers, large growths etc
- Neurological symptoms esp in spinal cord compression

# Common sites with cancer for Radiotherapy

- Cervix
- Genitourinary
- Gastrointestinal
- Breast
- Lympoma
- Kaposis sarcoma
- Head and neck

# Indications for surgery

- For diagnosis e.g. staging laparatomy in carcinoma of the cervix
- Local control of the disease e.g. debunking ovarian carcinoma
- Control discharge or haemorrhage e.g. repair of VVF
- Control pain or other symptoms e.g. relief/relieve obstruction in colonal cancer

# Potential burden of surgery

- Partial removal of cancer may lead to poor healing, wound dehiscence and infection
- May result in large tissue deficit with insufficient normal skin to close the wound
- Exposing the patient to operative risk without definite benefit
- Financial burden

# DEATH AND DYING (END OF LIFE CARE)

Death is the permanent ceassation of all the biological functions that sustain a particular living organism

Even if it’s obvious that one day we shall all die, we all never want to experience death or see our loved ones dying. Individuals react differently when they realize they are soon dying especially with terminal illness. Death remains a mystery throughout our lives

# Fears

There are many fears as the condition of the patient weakens such as;

- Fear of not being able to cope with the death event
- Fear of the patient dying in pain and agony
- Fear of in some way being responsible for the illness
- Fear of being alone in the house at the time of death
- Fear of how the others will survive when the loved one is gone
- Fear of what will happen after death
- Fear of the unfinished business or tasks the pt was undertaking
- Fear of staying in the house when the loved one is gone

# Points of care

- First assess your own fears honestly and enlist team support
- Listen actively to the pt & family, addressing their concerns
- Keep in mind the different emotional responses: shock, denial/disbelief
- Anger, guilt, depression, anxiety, acceptance, resignation
- Give any anticipatory guidance for the pt and family on what to expect

# Identifying signs of a patient approaching death

Signs of impending death with appropriate care

1. **Decreasing social interaction**

Many dying pts tend to be withdrawn but they remain aware of their surrounding until the time of death. Pts can be confused about time, mumbling, restless and may be claiming to see things which others are not seeing. It's thought that these could happen as a result of multiple organ failure, electrolyte imbalance, failing circulation & closeness to the next world. ↓sing social interactions & food & fluid intake. At this stage the pt no longer has appetite or feels hungry but may feel a little thirsty

# Cont'

**While caring for such a patient, always;**

- Explain to the family what is happening and encourage the family to allow the patient to rest
- Continue with care and keep surrounding familiar to the patient
- Encourage the family to use therapeutic touch (i.e. holding hands etc)
- Encourage the family to be observant
- Continue skin care, with explanation & teaching
- In case pt is experiencing pain, do not stop analgesics & monitor pain relief carefully (only reduce dosage)
- It's important that you respect the patient's wishes

# Cont’

- Keep the patient’s mouth clean and moist
- Be able to support and address the patient’s family concerns
- Encourage the family to continue talking to the patient, saying farewells, giving permission to let go of life peacefully

# Cont’

**2. Respiratory changes**

The patient may have changes in the breathing pattern e.g. chyne-strokes respiration, grunting and death rattle. It results from accumulation of saliva and oropharyngeal secretions leading to gurgling respiration. In such cases teaching caregivers about the importance of good oral care will ensure comfort

# Cont’

**3. Nearing death awareness**

This is special knowledge about the process of dying, what dying is like and what is needed to die peacefully.

Patients may describe or discuss being in the presence of some one who is already dead, seeing a place, knowing or choosing when death will occur, needing reconciliation and preparing for travel or change

# Cont’

**4. Inability to close eyes**

Patients may lose the ability to close their eyes while asleep, w/c can be very disturbing to the family members. This can commonly occur in pts who are severely wasted or fat. As a care provider you need to maintain eye moisture with artificial tears or normal saline drops or moist cloth covering the eyes

# Cont'

**Other signs**

5. **Decreasing fluid and food intake** (pt no longer has appetite or feels hungry)
6. **Changes in elimination** (urine production decreases or ceases)
7. **Circulatory changes** (extremeties are cold, sometimes appears greyish
8. **Pain,** Do not stop analgesics & monitor pain relief carefully (only reduce dosages; side effects may be more prominent at this stage)

# Cont’

**Remember that;**

- The patient can still hear at such a moment even if comatose
- Dying people always have periods of agitation
- And terminal delirium with fluctuating course

# Cont'

**Help provide psychosocial and spiritual support**

Offer pts' active listening, counseling and social/ emotional support.

Spiritual support is very important: be prepared to discuss spiritual matter if pt would like to

- Learn to listen with empathy
- Understand reactions to the losses in their life(the different stages of grief)
- Be prepared to "absorb" e.g. anger projected on to the health worker

# Cont’

- Connect with spiritual counselor or pastoral care according to the pt’s religious beliefs, praying together may be appropriate
- Protect your pt from over enthusiastic evangelists
- For some pts, it’s better to talk about meaning of their life, rather than directly about spirituality or religion

# Cont’

**Empower the family to provide care**

- As human beings, we know how to care for each other. Reassure the family caregivers that they already have much of the capacity needed
- Give information and skills

# Special advice for end of life care

**Preparing for death**

- Encourage communication within family
- Discuss worrying issues such as custody of children, family support, future school fees, old quarrels, funeral costs
- Tell the pt that they are loved and will be remembered
- Make sure pt gets help with feelings of guilt and regret
- Connect with spiritual counselor or pastoral care as pt wishes

**Presence:**

- Approach, be present with compassion
- Visit regularly
- Some one needs to hold hand, listen and converse

# Cont’

**Caring**

- Provide comfort
- Provide physical contact by light touch, holding hand

**Comfort measures near the end of life**

- Moisten lips, mouth and eyes
- Keep pt clean and dry
- Only give essential medications-pain relief, anti diarrheal, treat fever
- Control symptoms with medical Rx as needed to relieve suffering
- Eating less is ok and
- Skin care(turning every 2hrs  or more frequently)

# Signs of death

- Breathing stops completely
- Heart beat and pulse stop
- Totally unresponsive to shaking, shouting
- Eyes fixed in one direction, eyelids open or close
- Changes in skin tone-white to grey

# GRIEF AND BEREAVEMENT

**Grief: I**s the emotional and psychological experience activated by loss of something dear

Grief is a natural response to loss. It's the emotional suffering you feel when something or someone you love is taken away. It's felt by an individual, family or community brought about by loss: most intensely with the death of a loved one (HAU, 2011)

# Cont’

**Bereavement: I**s the state of having lost some one or something dear. The experience of someone who is grieved or bereaved is entirely individual. The way a person grieves depends on a number of factors such as ones personality and coping style, life experience, faith, and the nature of the loss

# Cont’

**Stages of grieving**

- **Denial.** Refusal to believe that death would be the likely outcome of this illness. No, not me, the tests must be wrong. God would not allow this to happen to me. There has been some mistake
- **Anger.** Questioning ‘why me?’ it’s not fair. Who or what can I blame for this illness

# Cont’

- **Bargaining.** Attempt to delay the disaster, Yes, but.. ‘if I give money to the church or pray and fast every day then I will recover
- **Depression**. Reaction to existing and impending illness. ‘it’s me, what’s the point of struggling on; it’s all meaningless.
- **Acceptance.** Peaceful resignation, it’s part of life. I have to get my life in order

# Cont'

**Grief can be;**

a) **Normal grief.** This is normally exhibited by feelings of anger, numbness, disbelief, depression & despair along with physical symptoms like overwhelming fatigue, poor sleep & impaired concentration
b) **Abnormal (complicated) grief.** May be delayed, inhibited, disenfranchised or prolonged
c) **Anticipatory grief**. Grief symptoms don't begin with the death of a loved one, rather as soon as symptoms develop that are perceived as threatening. Can be seen in both the dying & those close to the person

# Cont’

**The bereavement process:**

The following four tasks must be accomplished for satisfactory conclusion to the work of bereavement;

- Accept the reality
- Working through the pain of grief
- Adjust to the environment in which the deceased is missing
- Emotionally relocate the deceased and move on with life

# Manifestations of grief

| Somatic | Social | Psychological |
|---|---|---|
| •Loss of appetite<br>•Sleep disturbance<br>•Crying<br>•Lack of strength<br>•Physical exhaustion and lack of strength<br>•Loss of sexual desire or hyper sexuality<br>•Heart palpitations<br>•Shortness of breath | •Restlessness<br>•Painful inability to initiate and maintain organized patterns of activity<br>•Social withdraw | •Numbness<br>•Confusion/unsure of what to do<br>•Sadness<br>•Disbelief<br>•Anxiety<br>•Anger<br>•Guilt<br>•Searching or calling out for the deceased<br>•Dreaming about deceased<br>•Seeing, hearing or feeling the presence of the deceased |

# Counseling and management of grief/ bereavement

**Bereavement counseling**
**For patient**

- Look and respond to grief reaction-denial, disbelief, confusion, shock, sadness, bargaining, anger, humiliation, guilt, acceptance
- Keep communication open-If pt doesn't want to talk, ask, would you like to talk now or later
- Help the pt accept his/her own death
- Offer practical support. Help pt in making a will, solve old quarrels and plan for children's custody
- Ask them how they wish to die; with pastoral care or with family only
- Make sure that what the patient wants is respected

# Cont’

**For family**

- Look for and respond to grief reactions: denial, disbelief, confusion, shock, sadness, bargaining, anger, humiliation, guilt, acceptance
- Help the family accept the death of the loved one
- Share the sorrow-encourage them to talk and share the memories
- Don’t offer false comfort-offer simple expressions and take time to listen
- Try to see if friend or neighbour can offer practical help- cooking, running errands can help in the midst of grieving

# Cont’

- Ask them if they can afford funeral costs and future school fees, and help finding a solution if possible
- Encourage patience-it can take long to recover from a major loss
- Say that they will never stop missing the loved ones, but pain will ease and allow them to go on with life

# Management of grief/bereavement

- Embody hope
- Convey support/compassion
- Acknowledge the loss
- Accept the inability to control emotions
- Validate the range of feelings, thoughts and behaviours
- Plan efforts to channel energy into adapting to re-establish an equilibrium
- Encourage continued movement forward by accessing helpful people when required

# What you can do at the time of death

- Encourage family members to stay with the deceased for as long as they need
- Encourage the family members to hold the pts hands or say goodbye in whichever way they want
- Don't refer to the deceased as 'the body' but by his/her name
- If the family wasn't present at the time of death, give as much detail as possible
- Make sure a religious person is present if required
- Take time, go slowly
- Involve children and explain to them what is happening
- Be comfortable with expression of feelings e.g. crying etc

# What to do during bereavement

- Encourage family members to talk to each other and to share feelings such as guilt, relief, pain or anger
- Listen rather than talk
- Discourage a bereaved person from making big decisions like change of job, home, town. Their emotional state makes it hard for practical decisions to be taken
- Encourage the use of rituals that help channel the grieving process
- Be aware of your own losses and feelings
- Encourage family members to tell you about the person who has died

# What you should not do

- Don’t tell family what they should or not do
- Don’t panic when strong emotions are expressed or w/n there is a lot of crying. Just listen and try to understand
- Don’t tell grieving family how they should feel. Every experience is different
- Don’t talk about your own experience
- Don’t’ make a bereaved person feel you are in a hurry
- Don’t use phrases like ‘God takes the best’ or time will heal as the bereaved don’t find them useful
- Don’t tell the bereaved person that they will get over this
- Don’t stop a grieving person from crying

# Children's grief and bereavement

- Children are repetitive and ask questions over and over
- They act out their feelings rather than being able to express them in words
- Children may need to work through grief over and over at different stages in their life

# Things to say to children

- Death is universal and inevitable(use example from nature-flowers, leaves)
- Death can be unpredictable
- It’s okay to wish the person had not died
- It’s okay to be angry and sad
- Rely on religion and beliefs to accept and understand
- Don’t be afraid to use the words ‘dead’ or death
- assure the child about things in their that will not change e.g. same room, school, toys and friends
- Admit we all don’t have answers
- Emphasize that life continues after pain. There will be happy times again

# Things not to say to children

- The deceased is ‘sleeping’ or has been lost. This is confusing & frightening to children
- The deceased ‘wanted’ to go to heaven. This suggests the deceased had a choice in the matter and wanted to leave the child
- Don’t try to stop the grieving process. ‘big boys don’t cry’, be careful what you say, young children are very concrete. Saying God took the person can be very bad & could even cause the child to be angry with God, rather than finding comfort from God

# The role of the nurse/midwife in grief and bereavement

- Listen actively without judgment
- Encourage gentle exploration of what the future may look without the deceased
- Assess and encourage the development of social support system
- Encourage time with the body of the deceased at the time of death
- Respect survivors feelings without judgment
- Assist in identifying manifestations of grief & normalize them
- Assist the survivor in further identifying the meaning of loss in practical means

# BREAKING BAD NEWS

It’s any news/information that drastically and negatively alters the pt’s view of his/her future

**Importance**

- To maintain trust
- To reduce on uncertainties(false hopes)-the hardest of emotions to bear
- To prevent inappropriate hopes
- To allow appropriate adjustments so that the pt can make informed decisions

# Why breaking bad news is difficult

- There is fear of being blamed
- Fear of causing pain
- Fear of saying I do not know
- There is fear of expressing empathy/emotions
- Fear of not having enough time

# The six step protocol of breaking bad news

**Step 1: Getting started**

- Getting the physical context right
- Where you will carry out the message from
- Who should be there

**Step 2: Finding how much the patient knows**

- Extract pt's understanding about his/her status
- Check emotional contexts i.e. listening carefully and observing the patient's reaction

# Cont'

**Step 3: Finding how much the pt wants to know**

Use appropriate questions e.g. would you like me to tell you more about your condition?

**Note;** Remember sometimes people will be denial, so don't push information if they don't want it

**Step 4: Sharing information**

- Make sure you have enough information about the pts condition & the pt's history
- Start from the pt's starting point entry
- Educate i.e. give information in small bits, use non medical language, check that they have understood & reinforce information

# Cont’

**Step 5: responding to the patient’s feelings**

- Identify & acknowledge their reactions. Allow them to cry or do anything they wish
- Give them time to think
- Let them ask you questions

**Step 6: Planning and following up**

- Identify options or source of support
- Help them to make plans
- Offer future contact

# Psychosocial issues and counseling needs

Psychosocial issues or needs are issues that involve one's mind or environment. There are very many psychosocial issues that need counseling and these may result from within the pt or outside the patient's mind. These include;

- A person experiencing symptoms as a result of HIV infection may easily be overwhelmed by painful feeling
- Uncertainties exist for such individual as to whether or not they will remain
- The patient may experience multiple losses

# Cont’

- A loss of physical capabilities or normal functioning may become a major issue due to preoccupation
- The nurse should allow the patient to express his/ her thoughts, concerns or feelings
- Through active listening, the nurse can facilitate the problem solving that may occur, the patient expresses feelings and worries
- The patients should be supported & encouraged in all situations

# Cont’

- The potential isolation of pts by friends and family, fearful of coming into contact with them, can further compound the hopelessness that a pt feels w/n becoming ill with a life threatening disease
- One of the most therapeutic events for a sick person is his/her return to a normal life
- Some times the feelings of despair may be so great that suicide is perceived as the only means of gaining control or putting an end to painful feelings

# IMPORTANCE OF A WILL IN MATTERS OF INHERITANCE

**Introduction**

Quite often death robs us of our dear ones, leaving us behind with broken hearts. More so for children & their mothers(orphans and widows) who are so much emotionally torn apart that they tend to be sure of their survival of future on the death on the death of the breadwinner.

The department of child care protection(probation & social welfare) usually advise parents to prepare for the process of inheritance of whatever property the deceased could have had in his/her life

# Cont'

**What is inheritance?**

It's the process by which property left by the dead person is shared out among specified persons according to the wishes of the dead person or according to the manner laid down in the law. There are two ways of inheriting:

- Where there is a will left by the dead person
- Where there is no will

# Inheritance under a will

**What is a will?**

This is a document w/c expresses the wishes of the person and how his/her property is to be shared among the people/persons named in the document after the owner of the property died

The WILL can also contain other things that the person making it would like to be buried, it may give the name of the person who will be responsible for making sure that the wishes of the person are carried out once he dies

# Who can make a will?

A will can be made by anyone, male or female, married or single but the person should be:

- 21yrs old or above
- Of sound mind
- Not drunk at the time of making it
- Aware that he/she is making it

A will is not recognized in law if it's made by a person who is;

- Below 21yrs of age
- Was mad at the time of making it
- Was too sick to know that he/she was signing his/her will

# In what form can a will be made

A will should be in writing. It can be hand written by oneself. If the person making the will can't write, he/she can ask another person, who he/she trusts, to write and he/she tells the writer what to write. A lawyer can also write it on payment of his/her fees.

# What should a will contain?

- State your name and the place where you live
- State the day, month and year when you are making it
- The list of all the property you have should be shown
- Name your wife(wives) and all your children

**Note; The property you list down should be your own and not of another person**

- If anybody owes you anything(debt), name him/her saying what is owed and whether it should be paid back
- If you owe anybody, name the person and what you owe and how to pay him/her back

# Cont'

- State who will be guardian of your children if they are still young
- Name one or two persons who should carry out your wishes as stated in the will. Such person or persons are called EXECUTOR(S)
- You should sign the will. It's advisable to sign all the pages of the will to prevent forgeries. Number the pages accordingly
- If you can't write, you can thumb mark it
- Two people(witnesses) should see you signing or thumb-marking the will. They are not supposed to read it
- The two witnesses should write their full names, addresses, occupations on the WILL and then sign it

# Cont'

**Who can witness a will?**

Any normal person who is 21 years and above

**NB:** Any person given something in the will shouldn't witness that because under the law he/she will not be allowed to get what is left for him/her in the will

**In what language should a will be written?**

You can write your will in any language you like but it should be a language you know well. It's important that you use a simple language

# Cont'

**Can you change your will?**

**Yes.** You can change your will at any time you wish, when you get or lose property, or when you have children whom you want to leave something to or when you re-marry(another wife)

When you write a brand new will, state the date of your old will and that it's cancelled.

**NB:** when you marry, the law says that previous will don't apply. There4 make a new will when you marry or whenever you marry another wife

# Where should a will be kept?

The original copy should be kept in a safe place such as;

- A bank “Safe Deposit Box”
- Offices of resident judges
- High Court Registry
- Administrative general’s office

You can also keep copies of your will with a trustworthy friend, a priest/Reverend etc

# Reasons for making a will

There are several reasons why one should make a will. They include the following;

1. A will makes sharing your property easy because you would have said how your property is to be shared out
2. It ensures that people will only be given what is allocated to them in the will & avoids questions & quarrels among relatives
3. It gives you a chance to give away all your property, even to those not known to relatives

# Cont’

1. Without a will, people end up losing a lot of property
2. It gives you a chance to say whether you owe anybody a debt and  how the debt is to be paid
3. You can also say who owes you & your relatives will make sure that  he is paid

# How will my property be shared if I have not made a will?

The law has provided the following ways of sharing your property. All the property is put together and taken as one whole, making 100 parts of 100%. These parts are then divided among;

a) The children; all the children of the dead person legitimate or illegitimate, share equally 75 parts or 75% of the property left
b) The widow(s) / widower gets 15 parts or 15% of the property plus the house where the family has been living
c) Dependants share 9 parts (9%) of the property. These dependants could be your relative or adopted children
d) The customary heir gets 1 part or 1%

# Cont'

**NB:** A widow is not a property and cannot be shared or taken by another male relative of a dead husband, although she can decide freely to remarry even within her former husbands clan

- A widow has the right to live in her former husband's home till her death or till she remarries. Anybody who tries to send her away breaks the law
- A widow's personal property, be it treated as belonging to household goods, should not be treated as belonging to the dead husband nor is it to be shared out among others

# *What is the work of the guardians?*

The duties of the guardian are as follows;

- To look after and guide the young children
- To look after the property of the children making sure it's used for the children only and that it is not misused
- When the child grows up they are to handover the balance of the property left to the owner and to show what it was used for and how it was used. The law says that a guardian who misuses property of a child, must pay it back

# What is the role of the L.C in matters of inheritance

***The role of the L.C relates to the following*** ;

- Protection of widows and children from relatives who want to take away their property
- Giving the letter providing death for the office of the Administrator General and the Court